Statewide Analysis Reveals Period of Well-Child Visit Attendance for Earlier Diagnosis of Autism Spectrum Disorder

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Objective To explore the relationship between well-child visit (WCV) attendance during early childhood and age at autism spectrum disorder (ASD) diagnosis using data drawn from a statewide all-payer claims database.

Study design We used a correlational study design with longitudinal data drawn from the Virginia All-Payer Claims Database. All children born in 2011 with a diagnosis of ASD were included (n = 253). Survival analysis determined the impact of WCV attendance on ASD diagnosis at each American Academy of Pediatrics-recommended early childhood visit, and the 5-year visit.

Results Survival analysis revealed a significant impact of WCV attendance at the 24-month, 3-, and 4-year visits on earlier ASD diagnosis. Children who attended the 24-month visit were diagnosed nearly 10 months earlier than those who did not. Overall, children with ASD attended fewer than 50% of visits during early childhood.

Conclusions Promoting consistent WCV attendance during early childhood is an actionable strategy for improving early identification of ASD. Further exploration is needed to determine barriers to visit attendance and the impact of patterns of early childhood WCV attendance on age of ASD diagnosis. Development and implementation of interventions to promote adherence to the American Academy of Pediatrics-recommended visits is needed. *(J Pediatr 2022;241:181-7)*.

The age at which a child is diagnosed with autism spectrum disorder (ASD) can alter treatment outcomes because of the significant impact of early behavioral interventions.[1] ASD can be reliably diagnosed as early as 12 months,[2] yet US nationwide data reports the median age of diagnosis (AOD) to be 51 months,[3] although it is decreasing. There are wide disparities in the mean AOD across different populations, ranging from as early as 3 to as late as 10 years old.[4] Later AOD is often related to the social determinants of health of the child, parent, or community where the child resides. Drivers of later diagnosis include being of non-white race,[5,6] living in a rural area,[5-7] having lower socioeconomic status,[6-9] and parental characteristics such as the age when parents initially note concerns[6] or lower parental education.[6,9] Children with more subtle autism symptoms, those with higher IQ, and those with better language skills may be more difficult to diagnose in early childhood.[8] Diagnostic determination may require standardized testing by autism specialists, resulting in even greater delays for many families because of provider shortages and uneven resource distribution.[10,11]

Exploring the impact of well-child visit (WCV) attendance during the 1- to 4-year age range may offer insight. WCVs provide multiple opportunities for early identification. The American Academy of Pediatrics (AAP) recommends WCVs at 12-month, 15-month, 18-month, 24-month, 30-month, 3 years, and 4 years. Developmental surveillance is conducted at periodic visits, with formal developmental screening recommended at 9, 18, and 24 or 30 months of age and at any point if a concern is raised,[12] and ASD-specific screening at the 18- and 24-month visits.[13,14] A widely used ASD-specific screening tool, the Modified Checklist for Autism in Toddlers–Revised, is validated for use in children up to 30 months of age.[15] A study evaluating a national sample of Medicaid-enrolled children with ASD revealed that those who attended all recommended WCV during infancy and early childhood were diagnosed 1.6 months earlier than those who missed visits.[16] However, most children do not attend all recommended pediatric WCVs.[17]

All-payer claims databases (APCDs) aggregate claims and administrative data from both public and private payers.[18,19] APCDs are a potentially rich source of

AAP	American Academy of Pediatrics
AOD	Age of diagnosis
APCD	All-payer claims database
ASD	Autism spectrum disorder
COVID-19	Coronavirus disease pandemic of 2019
DOB	Date of birth
ICD-9	*International Classification of Disease, Ninth Revision*
ICD-10	*International Classification of Disease, Tenth Revision*
WCV	Well-child visit

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data to help better understand patterns of health care utilization among children: nearly 95% of US children currently have some form of private or public insurance coverage.[20] Currently, 18 US states have a fully implemented APCD.[21] The purpose of this analysis was to conduct a statewide exploration of the relationship between WCV attendance at early childhood visits and age at ASD diagnosis using data drawn from an APCD.

Methods

This study was approved by the University of Virginia Institutional Review Board for Health Sciences Research. We used a retrospective observational design to conduct the study. The data source for this study was the Virginia APCD, which operates under the authority of the Virginia Department of Health. This claims-level dataset contains paid medical and pharmacy claims for approximately 4-4.5 million Virginia residents with commercial, Medicaid, and Medicare insurance, from 2011to 2017.[22] In addition to containing up to 70% of all commercially paid claims, the data includes 100% of Medicaid data for Virginia's children.

We extracted a longitudinal dataset that included all children born in 2011 who had a recorded diagnosis of ASD during the study period. Children with ASD were identified with *International Classification of Disease, Ninth Revision* (ICD-9) and *International Classification of Disease, Tenth Revision* (ICD-10) codes (299 or F84 and appropriate subcodes, respectively). The dataset was converted from a claims-level data set to a longitudinal patient-level data set using the date associated with each claim and a unique patient identifier available in the Virginia APCD.

Measures

AOD was the main dependent variable of interest and was calculated by estimating time to diagnosis using the earliest incurred date for an autism claim, and subtracting it from the child's date of birth (DOB). Each child's DOB was estimated using the first instance of ICD-9 and ICD-10 codes for live birth, newborn care, routine infant care, and circumcision. In the case that none of these were identified, we used a combination of codes to estimate DOB (**Table I**, available at www.jpeds.com).

We calculated WCV attendance for each child during early childhood visits (12-month, 15-month, 18-month, 24-month, 30-month, 3-year, 4-year), and the 5-year visit. First, we identified all WCVs using current procedural terminology codes 99382, 99392, 99383, 99393, Z00121, Z00129, V202, and V2031. Next, we determined the WCV based on the age of the child in days at the time of the visit. If the child's age was in the window of acceptable age range for a 12-month WCV, we categorized the visit as such. For the 12-month and each subsequent WCV, we defined the acceptable age range as the window between 30 days prior to the named visit up until 31 days before the next visit. **Table II** (available at www.jpeds.com) shows the exact age ranges used to classify each WCV. The attendance rate was calculated as number of visits attended, divided by total number of recommended visits during the study period.

Covariates were derived from the APCD dataset. Lower parental income and education, Black race, Hispanic ethnicity, rurality, and having either public insurance or being uninsured all have been shown to contribute to WCV disparities in the US.[17,23,24] Because of the nature of the data source, our dataset contained no parental information; thus, we used US Census data to determine an area-level estimate of poverty and education. The dataset contained robust insurance data, categorized as either Medicaid or commercial. We used the children's zip codes to derive area-level 5-year estimates from the 2015 American Community Survey of the percent of the total population living below the poverty line and the percent of the population 25 years or older who have earned a high school diploma (or equivalent). Using the zip code, we classified rurality 2 ways: as a binary variable using Rural-Urban Commuting Area codes[25] and as a continuous variable by estimating the proportion of developed land in each residential zip code; both estimates of rurality are associated with lower WCVs in Virginia.[23] We evaluated temporal stability of both rurality and insurance type, and determined that both insurance type and zip code were stable over the study period.

Statistical Analyses

Relationships among covariates were assessed using Pearson and Spearman correlations for continuous variables, Wilcoxon Mann-Whitney to test for differences in distribution of continuous variables between groups, and χ^2 tests for associations among categorical variables. We used the Kaplan-Meier method to assess the impact of missed WCVs on time to diagnosis. For each visit, we subset the data to patients who had not yet been diagnosed by the beginning of the visit window, estimated median time to diagnosis, and used the log-rank test to determine whether attendance at that visit was associated with time to diagnosis. This was done sequentially for each WCV. Similarly, we used Cox regression to estimate adjusted hazard ratios for the effect of visit attendance on time to diagnosis, and to evaluate whether individual- and zip code-level factors were associated with time to diagnosis. Because rurality and payer were associated, we assessed their interaction in Cox models, but the interaction was not statistically significant and, thus, excluded from final models. Zip code level estimates of parental poverty and education were nonsignificant and excluded from final models, but payer and rurality were retained in all models for consistency even though they did not always attain statistical significance.

Results

The dataset contained 43 761 unique patient identifiers, and 286 unique patients were identified with an autism code, with an observed a rate of diagnosis of 0.654%. Of the 286, we were

able to determine a DOB for 253. These children were included in the analysis. The mean AOD for the children was 46.7 months, with a SD of 17 months. The lower quartile was 31.7 months, and the upper quartile was 60.4 months. The mean age at diagnosis for patients with commercial insurance was 40.7 (95% CI 36.9- 44.6) months, and for patients with Medicaid it was 48.5 (95% CI 46.1-50.9) months (t test P value = .0009).

Our dataset contained no racial and ethnicity data; however, in our previous experience using this data source, even when the race variable was available, it was at least 75% missing. The rate of missing race data was higher than has been reported in other health administrative datasets; high levels of both missing and inaccurate race data has historically been, and continues to be problematic in health services research making these data of questionable value when available.[26,27]

Table III presents WCV characteristics of the 253 children diagnosed with ASD. Overall, during early childhood, 844 visits were attended out of a possible 1771 (47.7%). The 18-month and 3-year visits were the best attended (53.0%, 55.3%, respectively), and only 22.3% of children attended the 30-month visit. Among the children diagnosed with ASD, 47 had no WCVs, although approximately 20 of these had at least 1 problem-focused visit, and 14 appear to have had no visits at all prior to their initial ASD diagnosis. Rurality was not associated with AOD using both the binary rural-urban commuting area variable (χ^2 P = .21) and the continuous variables (rho = −0.02). However, analysis of the rural-urban commuting area code revealed that living in a rural area was associated with increased likelihood to have Medicaid (χ^2 P = .0031).

Table III. WCV characteristics of sample (n = 253)

Characteristics	n (%)
WCV attendance	
12-mo	131 (51.78)
15-mo	116 (45.85)
18-mo	134 (52.96)
24-mo	133 (52.57)
30-mo	58 (22.92)
3-y	140 (55.34)
4-y	132 (52.17)
5-y	112 (44.27)
Attended no WCVs	47 (18.58)
WCV associated with autism diagnosis	
<12 mo of age	1 (0.4%)
12-mo	0 (0%)
15-mo	2 (0.7%)
18-mo	15 (5.34%)
24-mo	24 (8.54%)
30-mo	37 (13.17%)
3-y	53 (18.86%)
4-y	52 (18.51%)
5-y	47 (16.73%)
>5-y	22 (7.83%)
Insurance	
Commercial	60 (23.72%)
Medicaid	193 (76.28%)
Rurality	
Rural	64 (25.30%)
Urban	189 (74.70%)

Survival Analysis

Survival analysis revealed an association between visit attendance and earlier AOD for several of the WCVs. Kaplan-Meier survival curves and log-rank tests consistently showed this association (Figure). The median difference in time to diagnosis ranged from 0.66 months earlier for children who attended (at the 18-month visit, which the majority of children attended), up to a maximum difference of about 10 months earlier (at the 24-month visit; Table IV). At each visit, the estimated median AOD was earlier for children who attended the visit. The 24-month and 30-month visits had the widest difference. in unadjusted analyses of children undiagnosed at the 24-month visit, for those who missed the 24-, 30-month, and 3-year visits, the mean (SD) age at diagnosis was 55.4 (15.3) months, nearly 9 months later than the overall mean diagnosis.

In Cox models adjusting for payer and rurality, we observed that beginning with the 24-month WCVs, attendance was associated with earlier diagnosis of ASD (Table V). The hazard ratios were similar across time, showing approximatley a 30%-40% reduction in "risk" of earlier diagnosis for the attending children, compared with children who did not attend the visit. At the earlier visits (12-month through 3-year), having private insurance was also associated with earlier diagnosis. The hazard ratios were consistent across time, showing a 70% increase in "risk" of earlier diagnosis for children with commercial insurance, compared with those with Medicaid. Rurality was not significant in any of the models. In Cox models neither percent of local population without a high-school diploma, nor percent of local population living in poverty was associated with time to diagnosis, although it is possible that if this data were available at the individual level, findings may have differed.

Discussion

Our study suggests that promoting WCV attendance across early childhood may be an important target for facilitating early identification of ASD. The gap in AOD for children who miss specific visits was as wide as 9.9 months a substantial amount of time during a critical developmental period in which interventions are most effective. Children with ASD who attend all recommended WCVs are diagnosed earlier than those with no well-child care.[16] Our study expands this work by identifying a specific time frame during which missing WCVs may put a child at higher risk for a significantly delayed diagnosis.

In our study, the gap in AOD for children who missed their 24-month visit was several times larger than the 1.6-month gap found by Daniels and Mandell.[16] However, their research used only Medicaid data, whereas our study also included privately insured children, a group that has been well

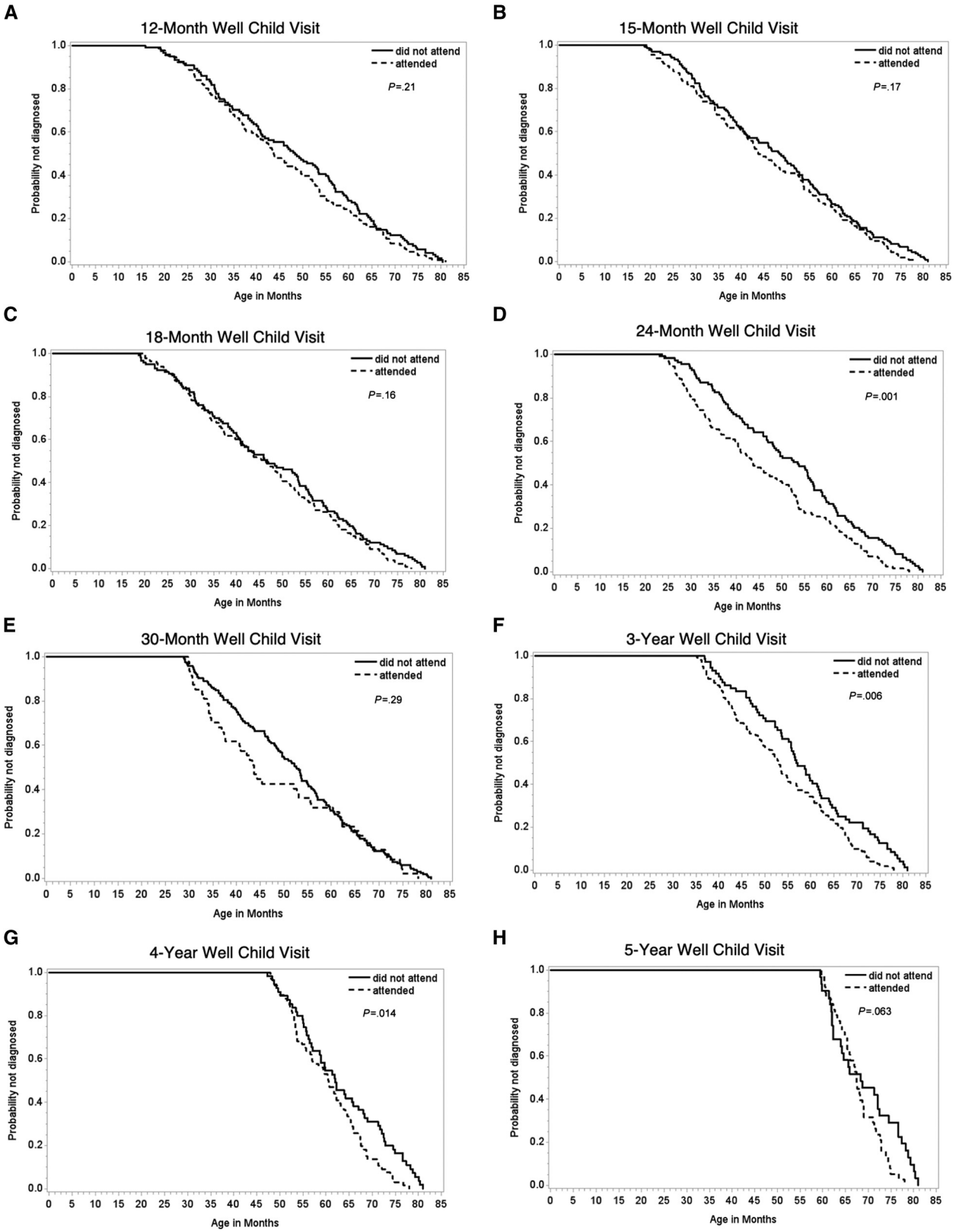

Figure. Kaplan-Meier survival curves show differences in the time to an ASD diagnosis for those who do and do not attend each WCV. Panels **D, F,** and **G** show significantly longer time to a diagnosis for those who do not attend the 24-month, 3-year, and 4-year WCVs. There is no difference in the time to an ASD diagnosis between those who do and do not attend the 12-month, 15-month, 18-month, 30-month and 5-year visits (Panels **A, B, C, E,** and **H**, respectively).

Table IV. Median time (in months) to diagnosis by visit, conditional on not yet being diagnosed

Visits	Number undiagnosed at beginning of visit window	Attendance	Median	95% CI	
12-mo	121	Did not attend	48.3943	40.9363	53.3552
	131	Attended	43.6961	39.7536	49.5770
15-mo	136	Did not attend	48.2300	40.9363	52.1725
	116	Attended	43.6632	40.0164	49.6756
18-mo	117	Did not attend	46.6858	40.8706	53.3552
	133	Attended	46.0287	40.5421	49.6756
24-mo	109	Did not attend	53.5195	46.9158	56.8049
	125	Attended	43.6304	40.2793	49.9713
30-mo	164	Did not attend	52.6324	48.7556	55.0965
	47	Attended	43.6304	37.3552	53.0924
3-y	72	Did not attend	56.9692	53.7166	61.3388
	102	Attended	53.1088	49.2813	55.6222
4-y	55	Did not attend	61.9959	57.1006	66.9897
	66	Attended	60.5010	56.6407	63.1786
5-y	31	Did not attend	68.3696	62.2587	72.4435
	38	Attended	67.4661	65.3799	68.9281

established to have higher attendance at WCVs compared with publicly insured or uninsured children.[17,23,24]

Medicaid coverage was a significant predictor of AOD at most visits. In our dataset, Medicaid coverage likely represents a proxy for working poor families. Since the expansion of public insurance to cover children whose families are uninsured but not living below the poverty line, more children are eligible to be covered by public insurance.[28] As such, the cohort of children with Medicaid in our study likely includes those whose parents work in low paying jobs that are, thus, less likely to have the flexibility to bring children to appointments.[29-31] To further children's attendance at WCVs, policies that support equitable access to paid sick leave are needed. In the absence of these policies, alternative methods of access such as accessible online portals for completion of developmental screening assessments and expansion of nontraditional clinic hours are needed.

Rurality did not impact AOD in our analysis, which may be explained by recent changes in access to both children's and rural population's insurance coverage.[32,33] In our study, rurality was significantly correlated with having Medicaid coverage, suggesting that recent gains in access to insurance may have mediated some of the barriers that rural children have historically experienced with seeking an ASD diagnosis. Further, our use of a binary rurality variable is a highly imperfect measure of geographic access. Future research

Table V. Hazard ratio for later age of diagnosis of ASD

Visits	Covariate	Hazard ratio	95% CI		*P* value*
12-mo	Nonattendance at WCV	0.891	0.690	1.149	.3728
	Payer (commercial vs Medicaid)	1.704	1.258	2.308	.0006
	Rural residence	1.071	0.831	1.380	.5942
15-mo	Nonattendance at WCV	0.824	0.668	1.015	.0690
	Payer (commercial vs Medicaid)	1.705	1.262	2.303	.0005
	Rural residence	1.057	0.822	1.360	.6660
18-mo	Nonattendance at WCV	0.879	0.680	1.136	.3254
	Payer (commercial vs Medicaid)	1.693	1.251	2.290	.0006
	Rural residence	1.044	0.811	1.344	.7384
24-mo	Nonattendance at WCV	0.649	0.498	0.846	.0014
	Payer (commercial vs Medicaid)	1.709	1.247	2.341	.0009
	Rural residence	1.012	0.779	1.313	.9301
30-mo	Nonattendance at WCV	0.858	0.602	1.223	.3972
	Payer (commercial vs Medicaid)	1.686	1.200	2.368	.0026
	Rural residence	1.095	0.814	1.472	.5497
3-y	Nonattendance at WCV	0.633	0.462	0.869	.0047
	Payer (commercial vs Medicaid)	1.856	1.272	2.707	.0013
	Rural residence	1.132	0.834	1.536	.4274
4-y	Nonattendance at WCV	0.655	0.445	0.963	.0315
	Payer (commercial vs Medicaid)	1.591	0.960	2.638	.0717
	Rural residence	1.199	0.822	1.747	.3464
5-y	Nonattendance at WCV	0.565	0.332	0.961	.0352
	Payer (commercial vs Medicaid)	2.393	1.159	4.941	.183
	Rural residence	1.082	0.660	1.774	.7539

*Level of significance set at .05.

should evaluate the impact of driving time to developmental pediatricians, as it may provide a more accurate proxy for the impact of geography.

Our use of the Virginia APCD dataset has several limitations. We were able to include data from 1 cohort resulting in a small sample, which was further limited to those we could identify using medical claim codes for ASD. Medical claim codes may exclude diagnoses made by community-based providers who do not bill insurance or those identified through the school system; however, prior research examining the validity of claims-based autism case identification has found relatively few false negatives.[34] Further, relatively fewer children are likely to have been identified by special education services under the autism category during early childhood without first having a formal diagnosis. Despite the dataset including all Medicaid claims data, not all insurers' data were included. For example, data did not include children insured by Tricare, which covers children of uniformed service members, retirees, and their families. We were unable to measure functional level at diagnosis, and because high functioning children are more likely to get a later diagnosis, these children may have been identified later in life. We were also unable to determine which children identified early had previously diagnosed siblings, which could have skewed the data to appear to be earlier.

The dataset was restricted to children under the age of 6 years, which excluded children with later diagnoses. Accordingly, the average age of diagnosis in the current sample was 46.7 months, lower than the estimated median age of diagnosis (51 months) in the larger population of children with ASD in the US.[3] In future studies, larger datasets spanning a wider window of time would allow for inclusion of a greater portion of the ASD population. It should be noted that the timeframe of the study spanned the transition from *Diagnostic and Statistical Manual of Mental Disorders, fourth edition* (DSM-IV) to *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* (DSM-5) (2013),[35,36] and the transition from ICD-9 to ICD-10 (2015). It is not clear whether these shifts in diagnostic criteria contributed differences in age of diagnosis across our cohort; however, ASD diagnostic concordance between DSM-IV and DSM-5 is generally high for young children.[37]

Finally, the data lacked several individual-level variables, including parental education and household income, which may have explained differences in WCV attendance and AOD that are important to future targeted intervention efforts. Although the dataset included race data, there was a high level of missing data, making it impossible to include as a covariate.

Our research highlights the importance of adherence to AAP recommendations for WCVs, particularly for Medicaid-insured children who are at higher risk of missing WCVs.[24] Practices serving a pediatric population should emphasize the importance of visits during the 2- to 4-year time frame. Overall, children in Virginia children attend just over one-half of recommended WCVs, and fewer than 30% attend the 30-month WCV.[23] The low attendance rates among our sample of children with ASD (47.7% overall; 22.9% at the 30-month visit) coupled with the wide time lag in AOD highlight the importance of these visits for conducting developmental screening. The recommendation to include a 30-month WCV was added in the AAP 2006 policy statement, which acknowledged that many children may miss the recommended 30-month visit, and suggested anticipating this gap and screening for ASD at the 18-month and 24-month visit.[12] It is unknown which insurance providers in Virginia cover the 30-month visit, and although anecdotally it appears most or all provide this coverage, confirmation may be warranted. In light of difficulties involved in anticipating a missed visit, attention needs to be focused on developing interventions to improve WCV attendance throughout early childhood, with renewed emphasis on the 2-year, 30-month, and 3-year visits. Successful interventions have been reported in the literature, including a *Reach out and Read* program and group visits.[38,39]

Finally, it is important for pediatric practitioners to consider the likely impact of the coronavirus disease pandemic of 2019 (COVID-19) on early childhood visit attendance and consequent ASD screening delays. During COVID-19, US children's vaccination rates dropped significantly for children over 2 years of age.[40] Although the impact of COVID-19 on ASD screening and diagnosis has not yet been evaluated, in the context of our findings, it is likely that diagnosis will be delayed for children across all groups, and further delaying care for those already at increased risk of late identification. ■

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Table I. ICD-9 and ICD-10 codes used to estimate date of birth

ICD or CPT code	Code description	DOB determination
99460	Initial day, normal newborn in hospital or birthing center	Date incurred
99461	Initial day, normal newborn in other than hospital or birthing center	Date incurred
99462	Subsequent day, normal newborn in hospital or birthing center	Date incurred +1
99463	Normal newborn care including admission and discharge on same day	Date incurred +1
99464	Delivery/birthing room attendance and resuscitation services	Date incurred +1
82247	Total bilirubin	Date incurred +1
99381	Initial comprehensive preventive medicine evaluation and management of an individual including an age and gender appropriate history, examination, counseling/anticipatory guidance/risk factor reduction interventions, and the ordering of laboratory/diagnostic procedures, new patient; infant (age younger than 1 y)	Date incurred + 60
99391	Periodic comprehensive preventive medicine reevaluation and management of an individual including an age and sex appropriate history, examination, counseling/anticipatory guidance/risk factor reduction interventions, and the ordering of laboratory/diagnostic procedures, established patient; infant (age younger than 1 y)	Date incurred + 60
54160, 54161, 54150, 54151, 54152	Circumcision	Date incurred +1
7364, V3000, V3001,	Cesarean delivery of newborn	Date incurred
V3900	Liveborn infant unspecified whether single, twin, or multiple, born in hospital without mention of cesarean delivery	Date incurred
7706	Transitory tachypnea of newborn	
V302	Single liveborn, born outside hospital and not hospitalized	Date incurred
V2032	Health supervision for newborn 8-28 d	Date incurred + 1
V3100	Twin birth, mate liveborn, in hospital	Date incurred
V2031	Health supervision for newborn under 8 d old	Date incurred +1

CPT, current procedural terminology.

Table II. Age ranges for categorization of WCVs (days)

Visits	Exact age	Lower end	Upper end
12-mo	365	335	424
15-mo	455	425	514
18-mo	545	515	694
24-mo	725	695	874
30-mo	905	875	1064
3-y	1095	1065	1430
4-y	1461	1431	1794
5-y	1825	1795	2189