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Brief Report: Estimated Prevalence of a Community Diagnosis of Autism Spectrum Disorder by Age 4 Years in Children from Selected Areas in the United States in 2010: Evaluation of Birth Cohort Effects

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Abstract

We compared early-diagnosed autism spectrum disorder (ASD) (defined as diagnosis by age 4 years) between the 2002 and 2006 birth cohorts, in five sites of the Autism and Developmental Disabilities Monitoring Network. In the 2002 cohort, the prevalence/1000 of early-diagnosed ASD was half the 8-year-old prevalence (7.2 vs. 14.7, prevalence ratio [PR] 0.5 [0.4–0.6]). Overall, the prevalence of early-diagnosed ASD did not differ between birth cohorts (PR 1.1 [0.9–1.3]). However, in three sites with complete case ascertainment, the prevalence of early-diagnosed ASD was higher for those born in 2006 versus 2002 (PR 1.3 [1.1–1.5]), suggesting possible improvement in early identification. The lack of change in two sites may reflect less complete case ascertainment. Studies in more recent cohorts are needed.

Keywords

Autism spectrum disorder; Autism; Prevalence; Birth cohort effects; Community diagnosis

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Author Contributions Dr. Soke conceptualized the study with inputs from the other co-authors. Dr. Soke analyzed the data and wrote the first draft of the manuscript. All the authors reviewed the manuscript and approved the final version of the article.

Disclaimer The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Compliance with Ethical Standards

Conflict of interest All authors reported no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study is a secondary data analysis of de-identified data previously collected in a surveillance system. Therefore, formal consent is not required.

Introduction

Autism spectrum disorder (ASD) is a chronic condition resulting in high societal costs (Lavelle et al. 2014). Studies have shown that ASD can be diagnosed by 24 months (Eaves and Ho 2004; Ozonoff et al. 2015) and early intervention services are associated with better outcomes (Anderson et al. 2014; Dawson et al. 2010; Eldevik et al. 2009). Though a decrease in the age of diagnosis has been documented over time (Christensen et al. 2016; Daniels and Mandell 2014), delays are still reported between the time of parental first concerns, evaluation, and diagnosis (Christensen et al. 2016; Sansosti et al. 2012; Shattuck et al. 2009). Therefore, increasing the proportion of children receiving a comprehensive evaluation by 36 months and those enrolled in special services by 48 months are Healthy People 2020 objectives (<https://www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health/objectives>).

In 2000, the Centers for Disease Control and Prevention started tracking the prevalence of ASD in 8-year-olds through the Autism and Developmental Disabilities Monitoring (ADDM) Network. In 2010, surveillance in 4-year-olds was added in a subset of ADDM sites to enable timely assessment of early identification of ASD. As part of ADDM data collection, all past diagnoses of ASD by community providers (e.g., developmental or general pediatrician, psychologist) are abstracted from medical and education records. We compared the estimated prevalence of early-diagnosed ASD (defined as diagnosis by age 4 years) between the 2002 and 2006 birth cohorts.

Methods

Sample and ADDM Methods

ADDM Network is an active, record-based surveillance system among 4-year and 8-year-olds in selected areas of the United States. In this analysis, we used data from the 2010 surveillance year. In 2010, 11 ADDM sites conducted surveillance of 8-year-olds, and among these, five also conducted surveillance of 4-year-olds. Our sample included data from the five sites that conducted surveillance in both 4 and 8-year-olds (Arizona, Missouri, New Jersey, Utah, and Wisconsin). These five sites had a total of 58,467 4-year-olds and 56,727 8-year-olds, representing 1.4% of 4 and 8-year-olds in the United States. The racial/ethnic distribution of ADDM sites mirrored their respective communities (Christensen et al. 2016).

ADDM Network uses a standardized, multi-step approach, described in details by others (CDC 2016; Christensen et al. 2016; Yeargin-Allsop et al. 2003). In short, during a surveillance year, health and education records of children who meet the age and residence requirements, have ICD and special education codes indicative of ASD or other developmental disabilities, are first screened for social deficits associated with ASD, a documented diagnosis of ASD, or eligibility for special education services. All evaluations of children meeting any of the above three screening criteria are abstracted verbatim, and evaluations from multiple sources are concatenated into a single file. At each site, expert clinicians review the composite abstraction file using an objective coding scheme based on the Diagnostic and Statistical Manual for Mental Disorders-IV-Edition-Text Revision (DSM-

IV-TR) criteria for ASD (APA 2000) to determine whether the child meets the ADDM case definition for ASD. Census data provide age-specific denominators to calculate prevalence.

Definitions of Key Study Variables

Not all ADDM sites have access to education records in their areas and must rely on abstraction of health records only to identify ASD cases. Past analyses have consistently shown that sites with access to health records only reported lower ASD prevalence than sites with access both health and education records, suggesting potential under-ascertainment of cases in the former group (CDC 2012; CDC 2016; Christensen et al. 2016). Of the sites included in this study, three (Arizona, New Jersey, Utah) had access to education and health records and were considered to have “more complete case ascertainment”, and two sites (Missouri, Wisconsin) had access only to health records and were considered to possibly have “less complete case ascertainment”. Education records included early intervention and also special education data for 4-year-olds, but only the latter for 8-year-olds.

While the majority of ASD cases have a documented ASD diagnosis from a community provider in their records, this is not required to meet the ADDM case definition. Across all five sites, 76% of 8-year-olds and 66% of 4-year-olds had a documented ASD diagnosis from a community provider in their records. In this study, a child was considered to have a documented ASD community provider diagnosis if their health or education records included a specific notation of a medical diagnosis of ASD by a qualified professional, such as a pediatrician or psychologist. Children whose records had an administrative ICD billing code or special education eligibility code indicative of ASD, but did not have a specific notation that a diagnosis was made by a qualified professional were not considered as having a documented community diagnosis of ASD.

Although there is no uniform definition of early diagnosis, here we define early-diagnosed ASD as a diagnosis by age 4 years. This is in keeping with the median age at diagnosis previously reported from ADDM (CDC 2016). Also, diagnosis by age 4 allows time for pre-school aged intervention services.

Participants

This analysis was limited to children from the five aforementioned sites who both met the ADDM case definition for ASD and who additionally were classified as having a community diagnosis of ASD documented in their records. All children in the 2006 birth cohort who met the above criteria were classified as early-diagnosed ASD since they were only 4 years of age during the 2010 ADDM surveillance year. All children in the 2002 birth cohort who met the above criteria were classified as 8-year-old diagnosed ASD because they were 8 years of age during the 2010 surveillance year and thus had received their community diagnosis by age 8; a portion of these children were also classified as early-diagnosed ASD if they received their community diagnosis by age 4. Thus, the following groups of children were examined:

- “Early-diagnosed ASD/2006 birth cohort” (n = 465)
- “8-year-old diagnosed ASD/2002 birth cohort” (n = 834)

- “Early-diagnosed ASD/2002 birth cohort” (n = 408)
- “Later-diagnosed ASD/2002 birth cohort” (n = 426)

Analytical Strategy

Log-binomial regression was used to compare (1) the prevalence estimate of “early-diagnosed ASD” in the 2002 and 2006 birth cohorts and (2) the prevalence estimate of 8-year-old diagnosed ASD versus early-diagnosed ASD in the 2002 birth cohort. We report prevalence and prevalence ratios (PR) for all sites, each individual site, three sites with more complete case ascertainment, and two sites with less complete case ascertainment. We also examined the characteristics of children with early-diagnosed ASD in 2002 versus 2006 birth cohorts and assessed significance of differences with Chi square tests for categorical variables and non-parametric median tests for continuous variables.

Results

For the 2002 birth cohort, the estimated prevalence (per 1000) of early-diagnosed ASD and 8-year-old-diagnosed ASD were 7.2 (95% CI 6.5–7.9) and 14.7 (13.7–15.7), respectively, (PR 0.5 [0.4–0.6]). These findings were consistent across sites (Table 1).

The overall prevalence estimate of early-diagnosed ASD in the 2006 birth cohort was 8.0 (7.2–8.7), which was similar to the early-diagnosed ASD prevalence estimate in the 2002 birth cohort (PR = 1.1 [0.9–1.3]), but site-specific PRs varied. Sites with more complete case ascertainment had a significant increase in early-diagnosed ASD in the 2006 birth cohort versus the 2002 birth cohort, while sites with less complete case ascertainment did not (Table 2).

Among the three sites with more complete case ascertainment, we noted several differences in children with early-diagnosed ASD who were born in 2006 versus 2002 (Table 3). Children born in 2006 were less likely to be non-Hispanic white and to have had a developmental regression than children born in 2002; they were also more likely to have low IQ and had younger median ages of both first known comprehensive evaluation and ASD diagnosis. In contrast, in the two sites with less complete ascertainment, the only difference between the birth cohorts was that children from the 2006 cohort were less likely to have had developmental regression in their records.

From the 2002 cohort, we compared characteristics of early-diagnosed children to later-diagnosed children. In both sites with more complete ascertainment and less complete ascertainment, later-diagnosed children were less likely than children with early-diagnosed ASD to have had a developmental regression (data not shown). Moreover, in sites with education data available, we found that later-diagnosed children were less likely to have an IQ < 70 compared to children with early-diagnosed ASD (data not shown).

Discussion

In the 2002 birth cohort, the prevalence of early-diagnosed ASD in the child records was lower than the prevalence by age 8 years. This finding was consistent across sites, regardless

of whether or not sites had access to education records in addition to health records. While some of this difference in prevalence between 4-year and 8-year-olds was expected, as some children will not show sufficient ASD symptoms to prompt an evaluation until they reach school years (Mandell et al. 2005; Mazurek et al. 2014), the magnitude of the difference nonetheless likely indicates a failure to identify some children who may manifest ASD symptoms at an early age. Like Jonsdottir et al. (2011), we found that in sites with the more complete ascertainment, children with IQ > 70, or those with no history of developmental regression were more likely to be diagnosed after 4 years. Therefore, these children may not receive an evaluation, or be diagnosed in time to receive services at critical windows of their development. Data on services were not available to directly evaluate to what extent this occurred.

Though the overall prevalence of early-ASD diagnosed was higher in the 2006 versus the 2002 birth cohort, the difference was not significant and we noted important variation between sites. Our findings extend those from Christensen et al., since we found that the lower median age at earliest comprehensive evaluation and ASD diagnosis in the 2006 birth cohort were limited to sites with access to special education records. Similarly, only the sites with access to special education records experienced an increase in the prevalence of children with a community diagnosis of ASD. In areas with the most optimal case ascertainment, we observed a 10–30% higher prevalence in the 2006 versus the 2002 birth cohort, suggesting a possible improvement in the diagnosis by age 4 in the 2006 birth cohort. This possible improvement is supported by both the lower median age at first comprehensive evaluation and ASD diagnosis in the 2006 birth cohort versus 2002 birth cohort. However, this increase may also be due to an overall increase in ASD prevalence in the 2006 birth cohort. Unfortunately, data are not yet available on ASD diagnosis after age 4 years in the 2006 birth cohort to evaluate this possibility. The differences in early-diagnosed ASD between the two cohorts might also be due to the inclusion of early intervention records only in the 2006 birth cohort. Children in the 2006 birth cohort were less likely to have a documented developmental regression than the 2002 birth cohort. The lower age at first comprehensive evaluation and diagnosis in the 2006 birth cohort may explain this difference, since developmental regression might have not been documented in children evaluated at a younger age.

Despite the improvement in early-ASD diagnosed noted in some sites, only about half of the children were diagnosed by 36 months and 80% had a comprehensive evaluation by 36 months. Although research indicates that a diagnosis of ASD can be made by 24 months (e.g., Ozonoff et al. 2015), some clinicians may not feel adequately trained and confident to diagnose ASD at younger ages (Golnik et al. 2009; Zuckerman et al. 2013). Heterogeneity in the clinical presentation of ASD at younger ages, lack of a biological test for the diagnosis, consequences of a false positive diagnosis, and lack of proper training may contribute to a reluctance for community providers to make an early diagnosis (Dosreis et al. 2006; Goin-Kochel et al. 2006; Zuckerman et al. 2013). Limited access to developmental assessment services, particularly before children reach school age, may be another contributing factor to diagnostic delays. Disparities in access to diagnostic services have been reported and may also contribute to diagnostic delays in specific populations (Liptak et al. 2008; Magana et al. 2013; Mandell et al. 2002, 2005).

This study is notable in using data from a large population-based sample of 4-year-old and 8-year-old children, whose records were reviewed by the same clinicians during the same surveillance year. However, it has some limitations. We only included children with a diagnosis of ASD in their records. It is possible that we missed children whose records could not be retrieved. In three sites where the prevalence of early-diagnosed ASD was different between the two birth cohorts, it is not currently possible to distinguish between possible improvement in early diagnosis and an overall increase in the prevalence of ASD in the 2006 birth cohort, since this analysis will require data, not available yet, on the 2006 birth cohort at age 8 years. Although these data are population-based, the generalizability of our findings is nonetheless limited, since ADDM sites are not selected to be a nationally representative sample.

Despite these limitations, our findings might inform policies and programs that target improvements in access to evaluation and diagnostic services. For instance, the ADDM data provide population-based indicators for early developmental assessment (e.g., 20% of children in the 2006 birth cohort did not receive a comprehensive evaluation by 36 months, with some site-to-site variability), which could be useful to efforts targeting improvement in access to evaluation and diagnostic services. Future studies based on ADDM data should track prevalence of early-diagnosed ASD in more recent birth cohorts, as data become available. Finally, our findings illustrate that although surveillance among 4-year old children provides much more up-to-date information about early ASD detection, it should not replace surveillance among 8-year-olds, as it only seems to capture half of the children ultimately diagnosed by the optimal age of 8 years (Yeargin-Allsopp et al. 2003).

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Table 1

Prevalence of early-diagnosed ASD and 8-year-old-diagnosed ASD in children born in 2002 and included in five sites from the 2010 ADDM Network

Sample	Prevalence/1000 of early- ASD-diagnosed (95% CI) in the 2002 birth cohort	Prevalence/1000 of 8-year-old ASD-diagnosed (95% CI) in the 2002 birth cohort	Prevalence-ratio (95% CI)
All 5 sites included in this study	7.2 (6.5–7.9)	14.7 (13.7–15.7)	0.5 (0.4–0.6)
3 Sites with access to both health and special education records (AZ, NJ, UT)	7.0 (6.2–7.9)	14.8 (13.6–16.1)	0.5 (0.4–0.6)
2 Sites with access to health records only (MO, WI)	7.4 (6.3–8.6)	14.5 (12.8–16.1)	0.5 (0.4–0.6)
Specific sites			
Arizona	4.3 (3.0–5.7)	10.0 (8.0–12.0)	0.4 (0.3–0.6)
New Jersey	8.7 (7.3–10.1)	16.1 (14.3–18.0)	0.5 (0.4–0.7)
Utah	6.5 (4.8–8.1)	17.2 (14.5–19.8)	0.4 (0.3–0.5)
Missouri	7.1 (5.7–8.6)	14.0 (11.9–16.0)	0.5 (0.4–0.7)
Wisconsin	7.9 (6.0–9.8)	15.2 (12.6–17.8)	0.5 (0.4–0.7)

CI confidence interval, *ASD* autism spectrum disorder, *ADDM* Autism and Developmental Disabilities Monitoring Network

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Table 2

Prevalence of early-diagnosed ASD in children born in 2006 versus 2002 and included in five sites from the 2010 ADDM Network

Sample	Prevalence/1000 of early-diagnosed ASD (95% CI) in the 2006 birth cohort	Prevalence/1000 of early-diagnosed ASD (95% CI) in the 2002 birth cohort	Prevalence-ratio (95% CI)
All 5 sites included in this study	8.0 (7.2–8.7)	7.2 (6.5–7.9)	1.1 (0.9–1.3)
3 Sites with access to both health and special education records (AZ, NJ, UT)	8.8 (7.9–9.7)	7.0 (6.2–7.9)	1.3 (1.1–1.5)
2 Sites with access to health records only (MO, WI)	6.4 (5.3–7.5)	7.4 (6.3–8.6)	0.9 (0.7–1.1)
Specific sites			
Arizona	4.8 (3.3–6.1)	4.3 (3.0–5.7)	1.1 (0.7–1.7)
New Jersey	11.1 (9.5–12.6)	8.7 (7.3–10.1)	1.3 (1.0–1.6)
Utah	8.5 (6.8–10.2)	6.5 (4.8–8.1)	1.3 (0.9–1.8)
Missouri	6.4 (5.0–7.8)	7.1 (5.7–8.6)	0.9 (0.6–1.2)
Wisconsin	6.3 (4.5–7.9)	7.9 (6.0–9.8)	0.8 (0.6–1.1)

CI confidence interval, *ASD* autism spectrum disorder, *ADDM* Autism and Developmental Disabilities Monitoring Network

Table 3

Characteristics of children with early-diagnosed ASD in children born in 2006 and 2002 and included in five sites from the 2010 ADDM Network

Characteristic	3 Sites ^a with access to both health and special education records		2 Sites ^b with access to health records only		p value	p value
	2006 Birth cohort with early-diagnosed ASD No. (%)	2002 Birth cohort with early-diagnosed ASD No. (%)	2006 Birth cohort with early-diagnosed ASD	2002 Birth cohort with early-diagnosed ASD		
Total	335	254	130	154		
Sex						
Male	266 (79.4)	211 (83.1)	102 (78.5)	130 (84.4)		
Female	69 (20.6)	43 (16.9)	28 (21.5)	24 (15.6)	0.26	0.20
Race/ethnicity						
Non-Hispanic White	146 (43.6)	142 (55.9)	88 (67.7)	111 (72.1)		
Non-Hispanic Black	62 (18.5)	34 (13.4)	12 (9.2)	18 (11.7)		
Hispanic	101 (30.1)	58 (22.8)	7 (5.4)	7 (4.6)		
Other	21 (6.3)	16 (6.3)	9 (6.9)	5 (3.3)		
Missing	5 (1.5)	4 (1.6)	14 (10.7)	13 (8.4)	0.04	0.55
Intelligence quotient						
≤70	48.7	36.2				
>70	51.3	63.8	Not Available ^c	Not Available ^c	0.007	-
Developmental regression						
Yes	82 (24.5)	78 (30.7)	31 (23.9)	58 (37.7)		
No	253 (75.5)	176 (69.3)	99 (76.1)	96 (62.3)	0.09	0.01
Median age of first known comprehensive evaluation	27 months	33 months	27 months	29 months	< 0.0001	0.75
Median age of first known ASD diagnosis	32 months	35 months	33 months	34 months	0.004	0.76

Significant values are given in bold at p < 0.05

CI confidence interval, ASD autism spectrum disorder, ADDM Autism and Developmental Disabilities Monitoring Network

^aThree sites (AZ, NJ, UT)

^bTwo sites (MO, WI)

^cIQ scores were not reported because of high proportion of missing data in the two sites without access to school records