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Prevalence of intellectual disability among eight-year-old children from selected communities in the United States, 2014

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ABSTRACT

Background: Children with intellectual disability (ID), characterized by impairments in intellectual functioning and adaptive behavior, benefit from early identification and access to services. Previous U.S. estimates used administrative data or parent report with limited information for demographic subgroups.
Objective: Using empiric measures we examined ID characteristics among 8-year-old children and estimated prevalence by sex, race/ethnicity, geographic area and socioeconomic status (SES) area indicators.
Methods: We analyzed data for 8-year-old children in 9 geographic areas participating in the 2014 Autism and Developmental Disabilities Monitoring Network. Children with ID were identified through record review of IQ test data. Census and American Community Survey data were used to estimate the denominator.
Results: Overall, 11.8 per 1,000 (1.2%) had ID ($IQ \leq 70$), of whom 39% ($n = 998$) also had autism spectrum disorder. Among children with ID, 1,823 had adaptive behavior test scores for which 64% were characterized as impaired. ID prevalence per 1,000 was 15.8 (95% confidence interval [95% CI], 15.0–16.5) among males and 7.7 (95% CI, 7.2–8.2) among females. ID prevalence was 17.7 (95% CI, 16.6–18.9) among children who were non-Hispanic black; 12.0 (95% CI, 11.1–13.0), among Hispanic; 8.6 (95% CI, 7.1–10.4), among non-Hispanic Asian; and 8.0 (95% CI, 7.5–8.6), among non-Hispanic white. Prevalence varied across geographic areas and was inversely associated with SES.
Conclusions: ID prevalence varied substantively among racial, ethnic, geographic, and SES groups. Results can inform strategies to enhance identification and improve access to services particularly for children who are minorities or living in areas with lower SES.

1. Introduction

Intellectual disability (ID) is a developmental disability characterized by limitations in intellectual functioning (e.g. learning, reasoning, problem solving) and adaptive behavior (e.g. conceptual, social, practical skills) that originates before 18 years.[1] Intellectual disability is estimated to affect 1%–3% of the population.[2–5] ID is a

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significant life-long disability. Functional limitations are broad, including language development, social interaction, motor skills, and self-care. Depending on level of impairment, children will have varying needs for support, from modified academic instruction and functional assistance to full-time care for daily living. Children with ID are more likely than typically developing peers to have co-occurring physical (e.g. asthma, ear infections, diarrhea, seizures, migraine or chronic headaches) and psychological (e.g. mood disorders, conduct disorders, anxiety disorders, attention deficit hyperactivity disorder) conditions.[6–9] The most common causes of ID are birth defects and genetic conditions such as Down syndrome, fetal alcohol syndrome, and fragile X syndrome. ID has been associated with older maternal age at childbirth and lower maternal education.[10–14] Studies have described an association between ID and lower socioeconomic status, particularly among black children and those with mild ID.[11,13,14] Approximately 30% of children with autism spectrum disorder (ASD), another developmental disability, also have ID.[15] Although previous studies have examined changes in how children with these conditions are classified over time[16–18] few have measured the proportion of children with ID that also have ASD.[19,20]

Previous estimates of ID prevalence among children in the U.S. have been based on national surveys[3–5] administrative records[21,22] or population-based data from a single state.[23,24] While these sources provide robust overall estimates, there is limited information on prevalence among sub-populations and in small geographic areas. In addition, national estimates are based on parent report, rather than empiric measurement. Our study extends current knowledge by 1) describing characteristics of ID among 8-year-olds, including tests administered, age at IQ test, severity, and presence of co-occurring ASD, 2) estimating the prevalence of ID among 8-year-old children by sex and race/ethnicity, and 3) describing variability in ID prevalence by geographic location and socioeconomic status. These data can increase awareness of the populations of children who are most affected with ID and inform strategies to improve early access to intervention and support services.

2. Methods

2.1. Population

The Autism and Developmental Disabilities Monitoring Network (ADDM) is a population-based surveillance system that estimates the prevalence of ASD and other developmental disabilities, including ID, among children in selected geographic areas (referred to as ADDM “sites”). ADDM staff screen records and abstract information from multiple data sources, including education programs and health care systems who evaluate and treat children with developmental disabilities. Sites in this analysis included 78 counties (range 1–48) in 9 states (Arkansas, Arizona, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, Tennessee) participating in ADDM in 2014 with access to records from both health and education sources. The population of this area included 215,514 8-year-old children (Supplemental Table 1).

2.2. ID and ASD classifications

ADDM methods are described in detail elsewhere.[15] In brief, records were identified for review if they contained ICD codes indicative of developmental disabilities, or if the child received services under specific categories in special education. Records were selected for ID abstraction if they contained results from an IQ test; all documented IQ and adaptive tests were abstracted. A child with ID was defined as a child with an IQ score ≤ 70 on the most recently administered IQ test. If multiple tests were given on the same date, the highest score was used to determine ID status. In the absence of an IQ score, a written statement by a qualified professional that a child’s intellectual functioning falls within the range for intellectual disability was accepted. Severity was classified according to Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria as mild (IQ 50–70), moderate (IQ 35–49), severe (IQ 20–34), and profound (IQ < 20).[25] When IQ was known to be ≤ 70, but a score was not listed, severity was defined as ID not otherwise specified (ID-NOS). Severe and profound ID were combined into a single category for analysis. Children were classified as having ASD if they met the surveillance case definition based on the DSM-IV-TR definition of ASD after clinical review.[15]

2.3. Race/ethnicity

Children were classified into race/ethnicity categories as follows: non-Hispanic black, non-Hispanic white, non-Hispanic Asian (includes Native Hawaiian/Pacific Islander), and Hispanic. These are referred to as black, white, Asian, and Hispanic.

2.4. Adaptive tests

Adaptive functioning was defined as impaired if any global score was reported to be ≤ 70. Because nearly a third of children were missing information on adaptive functioning, this criterion was not applied to the ID case definition used for this analysis. However, a sub-analysis using this definition was performed.

2.5. Denominators

County-level population estimates were obtained from the National Center for Health Statistics (NCHS) vintage 2016 bridged race estimates for 2014 and summed for the study area.[26]

2.6. Socioeconomic status (SES) variables

Median household income in the past 12 months (in 2014 inflation-adjusted dollars), educational attainment (percent of people 18 years or older with a Bachelor-level college degree or higher and percent with high school education or higher), poverty (percent below 2014 poverty level among all families with children under 18 years), and unemployment (percent unemployed civilian labor force 16 years or older) at the census tract level were included as measures of SES. SES indicators and census tract-level population estimates were obtained from the 2014 American Community Survey (ACS) 5-year estimates.[27] The population of 8-year-old children overall and for each demographic category was estimated by dividing the number of children aged 5–9 years by 5 for each census tract. For each SES variables, census tracts were weighted by the distribution of 8-year-olds and categorized into tertiles (low, medium, high). Children with ID were geocoded to their census tract of residence. Prevalence by tertile was determined by summing the number of 8-year-old children with ID in a tertile and dividing by the estimated number of 8-year-old children living in census tracts comprising that tertile.

2.7. Analysis

All editions of a test were combined into a single test name for analysis (e.g. Differential Ability Scales and Differential Ability Scales 2nd Edition). More information about which tests were included can be found in Supplemental Table 3. Median age at earliest and most recent IQ test was calculated. Distributions of age at first IQ test by severity, sex, and race/ethnicity were compared using the Kruskal-Wallis test and the Dwass-Steel-Critchlow-Fligner procedures. The proportion of children with ID and co-occurring ASD, adaptive testing scores, and adaptive impairment were described and compared across demographic categories using chi square tests (significance level $p < 0.05$). Prevalence [(cases/population) *1,000] and 95% confidence intervals was calculated overall and by sex, race/ethnicity, geographic site, and SES tertile. Prevalence was compared across categories using prevalence ratios, chi square tests (significance level $p < 0.05$) and the Cochran-Armitage Trend Test (for SES tertiles). All analyses were performed using SAS™ v9.4. A comparison of NCHS and ACS denominator values is shown in Supplemental Table 2.

3. Results

3.1. Characteristics of ID among 8-year-Old children in ADDM

Overall, across the 9 sites, 2,545 children had ID: 2,506 were classified based on scores from their most recently administered IQ test and 39 were classified based on a written statement provided by a psychometrist. A variety of IQ tests were given (Supplemental Table 3). Children were classified as having mild ID (78%), moderate ID (12%), severe or profound ID (1%), and for 8% the severity was not specified due to absence of a specific IQ score. Median age of a child at their most recent test was 70 months (5 years, 8 months), (25th-75th percentile, 51–90 months) (Table 1). Median age at the most recent test ranged from 64 months (5 years, 3 months) in New Jersey to 88 (7 years, 3 months) months in Maryland (Supplemental Table 4). Median age at a child's earliest IQ test was 56 months (4 years, 6 months) (25th-75th percentile, 35–72 months) (Table 1), varying from 33 months (2 years, 7 months) in North Carolina to 68 (5 years, 6 months) months in Maryland (Supplemental Table 4). Median age of earliest test for males was earlier than that for females (median 55 vs. 58 months; $p = 0.0279$), and white children (53 months) were tested earlier than black (58 months; $p = 0.0001$) and Hispanic (57 months; $p = 0.0080$) children (Table 1).

Eighty-six percent of children with ID had an adaptive test administered (Table 1). A variety of tests were given (Supplemental Table 3). Seventy-two percent of children with ID (n = 1,823) had composite scores available from an adaptive test. Availability of scores was similar by sex (male: 71%, female: 72%; $p = 0.6740$), but differed between white and black children (75% vs. 69%, $p = 0.0174$) (Table 1). Among children with scores, 64% (n = 1,164) were classified as having an adaptive behavior impairment. The proportion of children with adaptive impairment was higher among white compared to black children ($p = 0.0175$) and Asian compared to black ($p = 0.0016$), white ($p = 0.0334$), and Hispanic ($p = 0.0057$) children (Table 1).

A total of 998 (39%) children with ID also had ASD. This proportion was lower among females than males (27% vs. 45%; $p < 0.0001$), black compared to white children (35% vs. 43%; $p = 0.0025$), and Hispanic compared to white children (37% vs. 43%; $p = 0.0260$), and higher among Asians (55%) compared to white ($p = 0.0174$), black ($p = 0.0001$), and Hispanic ($p = 0.0004$) children (Table 1).

3.2. Prevalence of ID

In our study area, 51% of children were male, 46% white, 25% black, 22% Hispanic, and 6% Asian; this varied across sites (Supplemental Table 1). The prevalence of ID ranged from 8.0 per 1,000 in Minnesota and Tennessee to 16.1 per 1,000 in Arkansas, with an overall prevalence of 11.8 per 1,000 children (95% CI, 11.4–12.3) (Table 2). Prevalence per 1,000 children was 15.8 (95% CI, 15.0–16.5) among males and 7.7 (95% CI, 7.2–8.2) among females. Prevalence was 17.7 per 1,000 (95% CI, 16.6–18.9) among black children, 12.0 (95% CI, 11.1–13.0) among Hispanic children, 8.6 (95% CI, 7.1–10.4) among Asian children, and 8.0 (95% CI, 7.5–8.6) among white children (Table 3). The highest overall prevalence was seen among black and Hispanic males and the lowest among white females (Fig. 1). Black children had the highest prevalence of all race/ethnicity groups examined regardless of location (Table 3). Among children with mild ID, prevalence among black children (14.2 per 1,000) was 2.3 (95% CI, 2.0–2.5) times higher than among white children (6.3 per 1,000). This ratio was 1.7 (95% CI, 1.3–2.3) among children with moderate ID (black: 1.8 per 1,000; white: 1.1 per 1,000).

We observed an inverse association between ID prevalence and census tract-level SES, such that ID prevalence was generally lower across indicators of higher SES. Fig. 2 illustrates this pattern for

Table 1
Characteristics of intellectual disability among eight-year-old children, ADDM[a] 2014.

Demographic subgroup	N	Median age at IQ test, months (25th,75th percentiles)		Children with ID	Adaptive Behavior Functioning					
		Earliest	Most Recent	% have co-occurring ASD	Have adaptive test		Have scores from adaptive test		Have adaptive impairment	
Total	2,545	56 (35,72)	70 (51,90)	39%	2,180	(86%)	1,823	(72%)	1,164	(64%)
Sex										
Male (M)	1,727	55 (35,71)	68 (49,89)	45%	1,484	(86%)	1,233	(71%)	769	(62%)
Female (F)	813	58 (36,75)	73 (57,91)	27%	693	(85%)	587	(72%)	392	(67%)
p-value (M:F)		0.0279	<0.0001	<0.0001	0.6432		0.6740		0.0671	
Race/Ethnicity										
Black (B)	954	58 (37,76)	70 (52,90)	35%	804	(84%)	663	(69%)	398	(60%)
White (W)	800	53 (34,69)	71 (53,91)	43%	699	(87%)	597	(75%)	397	(66%)
Hispanic (H)	580	57 (37,71)	67 (49,91)	37%	484	(83%)	406	(70%)	252	(62%)
Asian (A)	104	54 (34,72)	65 (38,83)	55%	96	(92%)	75	(72%)	59	(79%)
p-value (B:W)		0.0001	0.9821	0.0025	0.0650		0.0174		0.0175	
p-value (B:H)		0.8978	0.5857	0.6568	0.6681		0.8353		0.5075	
p-value (B:A)		0.2454	0.0224	0.0001	0.0291		0.5809		0.0016	
p-value (W:H)		0.0080	0.8115	0.0260	0.0396		0.0570		0.1496	
p-value (W:A)		0.9978	0.0486	0.0174	0.1462		0.5815		0.0334	
p-value (H:A)		0.4498	0.1431	0.0004	0.0205		0.6637		0.0057	

[a] Autism and Developmental Disabilities Monitoring Network.

Table 2
Prevalence of intellectual disability per 1,000 eight-year-old children by site and Sex—ADDM[a], 2014.

Site	Population	Overall			Males			Females			M:F	
(No. Counties)		Cases	Prevalence	(95% C.I.)	Cases	Prevalence	(95% C.I.)	Cases	Prevalence	(95% C·I.)	Ratio	(95% C·I)}
Arizona (1[b])	24,952	245	9.8	(8.7–11.1)	163	12.8	(11.0–15.0)	82	6.7	(5.4–8.3)	1.9	(1.5–2.5)
Arkansas (48)	27,619	445	16.1	(14.7–17.7)	298	21.2	(19.0–23.8)	147	10.8	(9.2–12.7)	2.0	(1.6–2.4)
Colorado (1)	8,022	65	8.1	(6.4–10.3)	37	9.1	(6.6–12.5)	23	5.8	(3.9–8.8)	1.6	(0.9–2.6)
Georgia (5)	51,161	720	14.1	(13.1–15.1)	485	18.6	(17.0–20.3)	235	9.4	(8.3–10.7)	2.0	(1.7–2.3)
Maryland (1)	9,955	99	9.9	(8.2–12.1)	70	14.1	(11.1–17.8)	29	5.8	(4.1–8.4)	2.4	(1.6–3.7)
Minnesota (2[b])	9,767	78	8.0	(6.4–10.0)	54	10.9	(8.4–14.2)	24	5.0	(3.3–7.4)	2.2	(1.4–3.5)
North Carolina (6)	30,283	386	12.8	(11.5–14.1)	259	16.9	(15.0–19.1)	127	8.5	(7.1–10.1)	2.0	(1.6–2.5)
New Jersey (4)	32,935	341	10.4	(9.3–11.5)	241	14.3	(12.6–16.3)	100	6.2	(5.1–7.6)	2.3	(1.8–2.9)
Tennessee (10)	20,820	166	8.0	(6.9–9.3)	120	11.3	(9.5–13.5)	46	4.5	(3.4–6.0)	2.5	(1.8–3.5)
Total	**215,514**	**2,545**	**11.8**	**(11.4–12.3)**	**1,727**	**15.8**	**(15.0–16.5)**	**813**	**7.7**	**(7.2–8.2)**	**2.1**	**(1.9–2.2)**

[a] Autism and Developmental Disabilities Monitoring Network.
[b] Partial counties.

median household income; ID prevalence varied from 16.1 for children living in areas in the lowest tertile to 7.4 for those living in the highest tertile. This trend was statistically significant ($p < 0.0001$) overall, for males and females, and for white children across all five SES variables (Supplemental Table 5). Among black children, the association was significant for median household income ($p = 0.0017$) and high school education ($p = 0.0133$), but not for poverty (0.3299), unemployment ($p = 0.2839$), or bachelor-level education ($p = 0.0890$). Among Hispanic children, the association was significant for all SES variables except bachelor-level education ($p = 0.1475$), and for Asian children, the association held for all variables except unemployment ($p = 0.1851$). SES variables by race/ethnicity and cut-off values for each tertile are shown in Supplemental Table 6.

4. Discussion

Overall, 11.8 per 1,000 (1.2%) of 8-year-old children in our sample met criteria for ID, based on empiric measurement of intellectual functioning through collection and classification of test scores available for children living within defined geographic areas across 9 U.S. states. Our large sample size enabled us to calculate estimates for subgroups, and in doing so, we identified variability in ID prevalence by sex, race/ethnicity, and geographic location. Children who were in minority racial/ethnic groups or those that live in areas of lower SES generally had a higher ID prevalence. Demographic variability existed for ID prevalence estimates as well as age at first IQ test, availability of adaptive test scores, and proportion of children with co-occurring ASD.

Despite differences in ascertainment of ID status, sampling design, and participant characteristics, our findings are similar to those of previous studies. Our overall estimate is consistent with previous survey estimates in the National Survey on Children's Health (NSCH) in 2011–2012 (12.2 per 1,000) and the National Health Interview Survey (NHIS) in 2011–2013 (12.1 per 1,000) and 2009–2016 (11.1 per 1,000), but higher than NHIS estimates from 1997 to 2008 (7.1 per 1,000) which used different terminology ("mental retardation" rather than "intellectual disability") than recent surveys.[3–5] Our estimate is nearly identical to the administrative prevalence based on data from the U.S. Department of

Table 3
Prevalence of intellectual disability per 1,000 eight-year-old children by ADDM[a] site and race/ethnicity[b]– 2014.

Site	Population	Black			White			Hispanic			B:W		B:H		W:H	
(No. Counties)		Cases	Prevalence	(95% C·I.)	Cases	Prevalence	(95% C·I.)	Cases	Prevalence	(95% C·I.)	Ratio	(95% C·I.)	Ratio	(95% C·I.)	Ratio	(95% C·I.)
Arizona (1[c])	24,952	22	16.5	(10.8–25.0)	88	7.2	(5.8–8.8)	118	12.1	(10.1–14.4)	2.3	(1.5–3.6)	1.4	(0.9–2.1)	0.6	(0.5–0.8)
Arkansas (48)	27,619	117	27.3	(22.7–32.7)	259	14.0	(12.4–15.8)	44	11.5	(8.5–15.4}	2.0	(1.6–2.4)	2.4	(1.7–3.3)	1.2	(0.9–1.7)
Colorado (1)	8,022	13	12.8	(7.4–22.0)	10	3.8	(2.1–7.1)	41	10.2	(7.5–13.9}	3.3	(1.5–7.4)	1.3	(0.7–2.3)	0.4	(0.2–0.7)
Georgia (5)	51,161	404	18.3	(16.6–20.2)	108	7.0	(5.8–8.4)	138	13.9	(11.8–16.5)	2.6	(2.1–3.2)	1.3	(1.1–1.6)	0.5	(0.4–0.6)
Maryland (1)	9,955	48	14.1	(10.6–18.7)	31	6.2	(4.4–8.9)	8	9.7	(4.8–19.3)	2.3	(1.5–3.5)	1.5	(0.7–3.0)	0.6	(0.3–1.4)
Minnesota (2[c])	9,767	38	14.0	(10.2–19.2)	20	5.3	(3.4–8.2)	14	9.4	(5.6–15.9)	2.7	(1.6–4.5)	1.5	(0.8–2.7)	0.6	(0.3–1.1)
North Carolina (6)	30,283	157	20.4	(17.4–23.8)	118	7.7	(6.5–9.3)	62	11.4	(8.9–14.6)	2.6	(2.1–3.3)	1.8	(1.3–2.4)	0.7	(0.5–0.9)
New Jersey (4)	32,935	115	16.1	(13.4–19.3)	70	5.1	(4.1–6.5)	138	13.4	(11.4–15.9)	3.1	(2.3–4.2)	1.2	(0.9–1.5)	0.4	(0.3–0.5)
Tennessee (10)	20,820	40	9.5	(6.9–12.9)	96	7.4	(6.0–9.0)	17	6.0	(3.7–9.6)	1.3	(0.9–1.9)	1.6	(0.9–2.8)	1.2	(0.7–2.0)
Total	**215,514**	**954**	**17.7**	**(16.6–18.9)**	**800**	**8.0**	**(7.5–8.6)**	**580**	**12.0**	**(11.1–13.0)**	**2.2**	**(2.0–2.4)**	**1.5**	**(1.3–1.6)**	**0.7**	**(0.6–0.7)**

[a] Autism and Developmental Disabilities Monitoring Network.
[b] Excludes Asian Non-Hispanic and other groups due to small sample size.
[c] Partial counties.

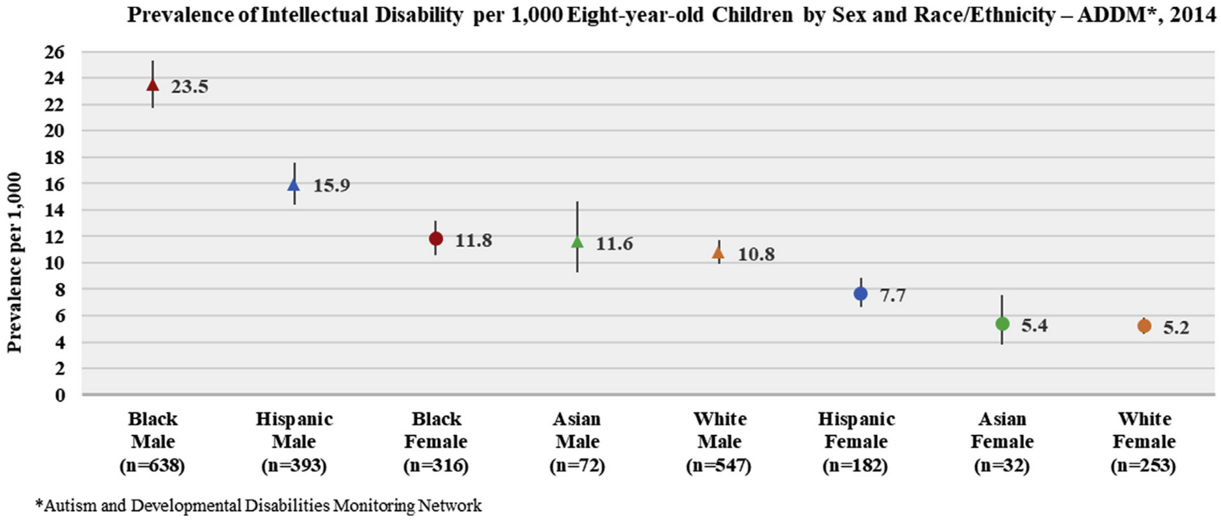

Fig. 1. Prevalence of intellectual disability per 1,000 eight-year-old children by sex and race/ethnicity - ADDM*, 2014.

Education for school-aged children over 20 years earlier, in 1993 (11.4 per 1,000).[21] Our current estimate is also consistent with records-based data among 8-year-olds in the Georgia ADDM site between 1985 and 1987 (12.0 per 1,000)[23] and only slightly lower than an estimate for this same area between 1991 and 2010 (13.3 per 1,000).[24] The prevalence among males in our study was double that of females and falls within the range of previous estimates showing ranges among males of 14.2–16.3 per 1,000 compared to females (7.8–9.6 per 1,000).[4,5,24] The predominance of ID among males is well-documented and likely due, at least in part, to biologic risk factors such as X-linked genetic conditions and increased vulnerability to adverse obstetrical events.[28,29] We also found that a much higher proportion of males than females had co-occurring ASD (45% vs. 27%, respectively), consistent with previous studies.[19,20] This finding is not surprising given the fact that ASD, in general, is reported much more frequently among males.

Disparities in prevalence of ID between white (lower prevalence) and non-white (higher prevalence) children have been reported consistently in the literature. Numerous explanations have been proposed, including differential socioeconomic status. Poor living conditions can create opportunities for environmental exposures or poorer nutrition which can impact perinatal outcomes. Family factors such as lack of financial resources, parenting style, and parental stress and depression result in less cognitive stimulation and reduced access to educational enrichment.[30,31] Stratifying ID prevalence estimates by census-tract tertiles did attenuate some of the racial differences in our analysis but could not completely account for all observed differences. Factors such as lack

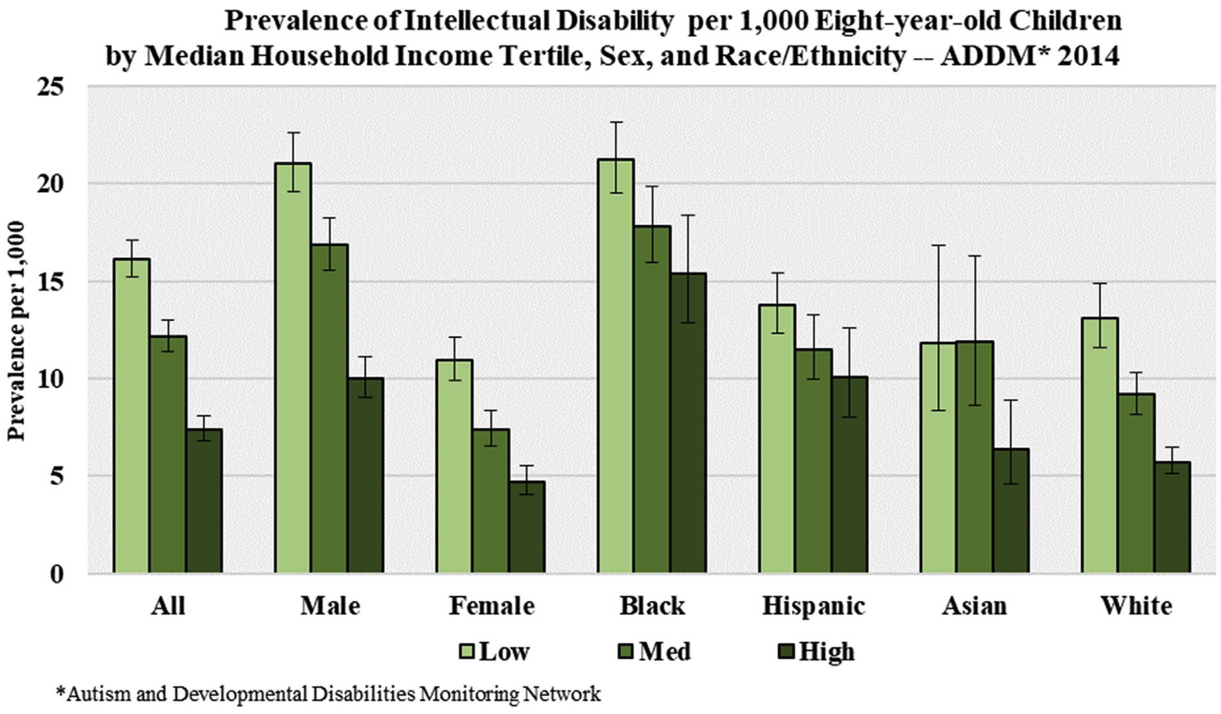

Fig. 2. Prevalence of intellectual disability per 1,000 eight-year-old children by median household income tertile, sex and race/ethnicity - ADDM* 2014.

of access to healthcare in order to receive evaluations or differential referrals for testing might help to explain the later age at earliest IQ test among black and Hispanic children in our analysis. Presence of co-occurring neurological conditions or lack of literacy and language skills could also play a role in racial differences.[13,32] Such factors are important to consider when examining the differences seen among children with mild versus moderate ID. Children with moderate ID have more substantial impairment and so may be likely to be referred for testing more equally by race or SES based on symptoms; however, identifying children with mild ID may depend more on these external factors.

We also found that prevalence of ID varies by geographic location, with higher rates observed in three of four ADDM sites in the southern U.S. This pattern is likely influenced by population distribution and socioeconomic factors, including access to diagnostics services, discussed previously, but differences in state-level education testing policies, may also influence availability of IQ data. Administration of IQ tests may be standard practice for receipt of special education services in some states or school districts, but not in others. Testing practices might also help explain the slightly higher (although not statistically significant) age at first ID test seen among those with severe/profound ID. It is possible that children with more severe impairment were already receiving services under different classifications so did not require IQ testing, or that their impairment made testing difficult at younger ages.

Our findings are subject to limitations. First, the ADDM case definition for ID did not include adaptive functioning scores which are included in other definitions.[1] While adaptive testing helps to determine a child's abilities and needs for support and is used to define ID severity based on DSM-5 definitions[33] a previous ADDM study found that adaptive scores may not be crucial for determining population prevalence.[34] Our sensitivity analysis indicated that when the adaptive functioning criterion was applied to ID case definition, a lower estimation of prevalence occurred yet overall patterns remained unchanged (data not shown). Second, access to educational records is limited by data use agreements which typically do not include private or home-schooled students. This could lead to an underestimate of ID prevalence if children who are home-schooled or attended private school were not identified through review of clinical sources. In addition, areas participating in ADDM are not representative of the entire U.S., thus caution should be taken when extrapolating results. Third, the number of eight-year-old children used in the SES denominator assumes that the number of children in each year of age is the same for all children aged 5–9 years. Thus, estimates could be affected if the distribution varies substantively within this age range.

Early identification and intervention are essential to the well-being of children with ID. Pediatricians play an essential role through routine screening and referral. Current guidelines emphasize the need for developmental surveillance at every visit and standardized screening tests at the 9 month, 18 month, 30 months, and 4-5-year well-child visits,[2,35.] While most cases of ID can be diagnosed well before 5 years of age[36] nearly one of four children in our analysis had their earliest test after 6 years of age. Strategies such as newborn screening and routine use of standardized developmental screening tools to improve early identification of ID and referral to services, particularly for minority children and those living in lower SES areas, could improve health and quality of life for children with ID and their families.

5. Conclusion

This study provides population-based, multi-site prevalence estimates for intellectual disability based on empirical data from children in the United States. Substantial disparities occur across racial, ethnic, and socioeconomic groups. Results could be used to help inform strategies to enhance early access to intervention services to improve quality of life for children with ID.

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Declaration of competing interest

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2020.101023.

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