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Patterns of Special Education Eligibility and Age of First Autism Spectrum Disorder (ASD) Identification Among US Children with ASD

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Abstract

The study examined timing of autism spectrum disorder (ASD) identification in education versus health settings for 8-year-old children with ASD identified through records-based surveillance. The study also examined type of ASD symptoms noted within special education evaluations. Results indicated that children with records from only education sources had a median time to identification of ASD over a year later than children with records from health sources. Black children were more likely than White children to have records from only education sources. Restricted and repetitive behaviors were less frequently documented in educational evaluations resulting in developmental delay eligibility compared to specific ASD eligibility among children with ASD. Future research could explore strategies reduce age of identification in educational settings and increase equitable access to health evaluations.

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Conflict of interest Amy N. Esler, Jeannette Sample, Jennifer Hall-Lande, Bryn Harris, Catherine Rice, Jenny Poynter, Russell Kirby, Lisa Wiggins declares that they have no conflict of interest.

Keywords

Autism spectrum disorder; Identification; Special education; Disparities

Since the first prevalence estimates were reported by the Autism and Developmental Disabilities Monitoring (ADDM) Network in 2000 (Centers for Disease Control and Prevention [CDC], 2007), autism spectrum disorder (ASD) detection has increased resulting in a 175% increase in measured prevalence with one in 44 8-year-old children with ASD in surveillance year 2018 (Maenner et al., 2021). Increased surveillance, the broadening of diagnostic criteria for ASD, and earlier diagnosis have contributed to but do not fully explain the increase in ASD prevalence, and reasons for the increase are multifaceted and not yet fully understood (Rice et al., 2010, 2012; Weintraub, 2011). Early diagnosis, and subsequent early intervention, are important public health goals as early intervention can improve developmental outcomes for children with ASD (Dawson et al., 2010, 2012; Landa, 2018; Wetherby et al., 2018; Zwaigenbaum et al., 2015). Though the importance of early identification is well documented (e.g., Dawson et al., 2012; Zwaigenbaum et al., 2015), the median age of ASD diagnosis remains later than desired. Median age of documented ASD clinical diagnosis has changed little since ADDM Network surveillance began, generally falling between 4 and 4 ½ years of age (ADDM Network Principal Investigators and CDC, 2009, 2012; Baio, 2014, Baio et al., 2018; CDC, 2007; Christensen et al., 2016; Maenner et al., 2020, 2021). Looking at this issue a different way, cumulative incidence of documented diagnosis among different age groups suggests ASD is being diagnosed earlier: incidence of ASD in 4-year-olds was higher than that of 8-year-olds in 2016, indicating more early identification of ASD in the younger group (Shaw et al., 2020), and other studies have also found lower mean age of diagnosis for younger cohorts compared to older cohorts (Daniels & Mandell, 2014).

Receipt of an early comprehensive developmental evaluation is an important step for early intervention; even if a diagnosis of ASD is not given, early evaluation can identify areas of delayed or impaired development to facilitate intervention and establish need for services. In 2016, only 44% of 8-year-old children who met ADDM Network case status of ASD were evaluated by age 36 months (Maenner et al., 2020), and this, too, has remained stable over the course of ADDM reporting (ADDM Network Principal Investigators and CDC 2009, 2012; Baio, 2014, Baio et al., 2018; CDC, 2007; Christensen et al., 2016).

Special education eligibility under the K-12 system requires the presence of an educational impact, and not all children clinically diagnosed with ASD will meet that criterion. Hence, the rate of children with ASD special education eligibility (e.g., one in 81 school-aged children in Safer-Lichtenstein et al., 2020) has typically been lower than estimates based on information documented in both health and education records (e.g., 2016 ADDM Network ASD prevalence of one in 54). However, schools are an important source of ASD identification, and a substantial minority of children are only ever identified through education evaluations. For example, using data from ADDM sites with access to both health and education records in 2002, 38% of children who met ADDM ASD case status had records that were located at education sources only (Pettygrove et al., 2013). In a study

examining surveillance year 2014 data, 11% of 8-year-old children who met ADDM ASD case status had a special education identification of ASD, but no clinical ASD diagnosis documented in their records (Wiggins et al., 2020).

Previous research has found differences in socioeconomic and demographic characteristics of children diagnosed with ASD based on different ascertainment sources (education versus health). Children identified in education sources only were more likely to live in neighborhoods with high mobility (Pettygrove et al., 2013), less likely to have mothers with at least a high school education (Bhasin & Schendel, 2007; Pettygrove et al., 2013; Yeargin-Allsopp et al., 2003), and more likely to have younger mothers (Yeargin-Allsopp et al., 2003). Regarding race/ethnicity, in a prevalence study conducted in metropolitan Atlanta, Yeargin-Allsopp et al. (2003) found that Black children who met ADDM case status for ASD were more likely than White children to have records from only education sources. Pettygrove et al. (2013) did not find that relationship in a study that included the full ADDM Network but did find that Hispanic children who met ADDM case status were more likely to have records exclusively from education sources. In addition, in Pettygrove et al., children with records from education sources only who met ADDM case status were less likely to have had a previous special education identification of ASD, suggesting that access to health evaluations for ASD may influence special education eligibility decisions.

Timing of ASD identification tends to be later in educational evaluations compared to health evaluations, with most analyses showing median age of first educational identification occurring after age 5 ½ or 6 years of age (Pettygrove et al., 2013; Shattuck et al., 2009). These demographic and socioeconomic differences in who is identified only in education sources, and the increased delay in ASD identification experienced in education sources, have the potential to contribute to disparities in access to intervention and achieving positive outcomes.

Evidence-based practice guidelines for assessment of ASD are similar regardless of whether an evaluation is conducted in an education or health setting (Akshoomoff et al., 2006; Campbell et al., 2014; Esler & Ruble, 2015; Huerta & Lord, 2012; Wilkinson, 2016). Studies examining outcomes of special education evaluations for ASD that used evidence-based assessment have generally found high agreement with independent health evaluation (Maddox et al., 2020). Evidence-based assessment involves obtaining a family medical/developmental history, conducting a physical evaluation, performing a vision and hearing screen, and evaluating multiple domains of developmental skills, including cognitive development, language, adaptive skills, behavioral-emotional development, and behavioral and developmental patterns specific to ASD (e.g., Filipek et al., 1999; Hyman et al., 2020; Klin et al., 2005; Volkmar et al., 2014). Those conducting ASD evaluations should use valid and reliable measures of ASD symptoms (Campbell et al., 2014; Esler & Ruble, 2015; Huerta & Lord, 2012), and a standardized, structured observation measure is usually recommended to aid in the identification of ASD (e.g., Huerta & Lord, 2012), such as the Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2; Lord et al., 2012). Despite having similar guidance, educational evaluations and medical evaluations are separate and parallel processes; being diagnosed medically with ASD does not equate to qualifying for

special education under the ASD category, and meeting criteria for the ASD category in special education does not equate to having a medical diagnosis.

Another consideration in timing of identification specific to educational settings is the option to use the nonspecific developmental delay (DD) category under the Individuals with Disabilities Education Act (IDEA) Parts C (special education for ages 0 to 3 years) and B (special education for ages 3 through 9 years or any subset of that age range). The DD category applies to children ages 0 up to potentially age 9 years who are "experiencing DDs as defined by the State and as measured by appropriate diagnostic instruments and procedures" in one or more of the following areas: cognitive development, physical/motor development, communication, emotional development, or adaptive skills (IDEA, 2004). The availability of the DD category does not preclude application of a specific disability eligibility category (such as ASD), and educational teams can evaluate for and apply a specific disability eligibility category to children under age 9 where applicable and appropriate (Danaher, 2011). All states implement Part C services, and 44 states include ASD as a specific eligibility category in addition to DD for infants and toddlers to receive special education services (Barton et al., 2016). A question is whether use of the DD category delays identification of ASD and thus access to targeted interventions and services specific to the needs of children with ASD.

States vary in their requirements for assessment tools and procedures for DD evaluations, and this has implications for whether concerns related to ASD are captured and described. Federal special education guidance indicates that states must use "appropriate" diagnostic instruments and procedures and assess "in all areas related to the suspected disability" (IDEA, 2004). Best practice guidelines suggest that evaluations of DDs should be comprehensive, including data from multiple methods, multiple sources, and multiple settings (Alfonso et al., 2020) and may include systematic direct observations, interviews, and norm-referenced tests (Salvia et al., 2017). Evaluations should cover the five developmental domains (cognitive, physical/motor, communication, social-emotional, and adaptive), and practitioners should be familiar with what is expected in typical development at various ages (Alfonso et al., 2020). Valid and reliable tools are necessary in order to make accurate eligibility decisions and to develop effective interventions (Alfonso & DuPaul, 2020; Hojnoski & Missall, 2020). Assessment with young children should be grounded in a developmental perspective, include multiple contexts, focus on the child's strengths as well as areas of concern, and be culturally responsive (Hojnoski & Missall, 2020).

Regarding assessing for ASD eligibility, little information exists on whether early childhood special education teams integrate autism-specific measures into DD evaluations when ASD is a concern, or whether needs related to ASD are assessed via general measures of social-emotional development. This information would shed light on whether the needs of young children suspected of having ASD are adequately covered in early childhood evaluations, regardless of whether the evaluation is designed for DD or ASD eligibility. The current study has two objectives: (a) compare age of first ASD identification and age of first comprehensive evaluation for children with ASD with records from education sources only to children with records from health sources only or from education and health sources, with attention to relationships with sex, race/ethnicity, presence of intellectual disability,

and ASD severity; and (b) describe and compare ASD symptoms and ASD measures documented in educational evaluations that resulted in DD eligibility and ASD eligibility among children who were determined to have ASD in ADDM.

Methods

The population for this study included 8-year-old children who had health and educational records reviewed for developmental evaluations from sites within the ADDM Network in surveillance year 2016 (award cycle 2015–2018). Only children with confirmed ADDM ASD case status living in school districts where educational records were reviewed were included in the analyses. The ADDM Network is funded by the Centers for Disease Control and Prevention (CDC) and included 11 sites in 2016; for the current study, sites were limited to those that had full access to educational records within the surveillance area and consistent documentation of record source (i.e., whether records were in health, education, or both sources). This resulted in 4 of the 11 (36%) sites being retained for analysis: Arizona, Georgia, Minnesota, and North Carolina.

In surveillance year 2016, the ADDM Network implemented an active, multiple-source, records-based public health surveillance methodology to monitor ASD prevalence in 8-year-old children (Rice et al., 2007). Case identification of ASD involved two phases. Phase 1, screening and abstraction, included all children born in 2008 who had at least one parent residing in the defined geographic surveillance area. Record review included educational records for children who had ever received special education services and clinic source health records from clinics where assessment, diagnosis, and treatment of various developmental disabilities (including ASD) occurred. Trained abstractors reviewed these records to identify behavioral descriptions that met specific inclusion criteria. Specifically, records were reviewed for behavioral descriptions that reflected Diagnostic and Statistical Manual-5th edition (DSM-5; American Psychiatric Association, 2013) symptoms of ASD —these are referred to as “social behavioral triggers.” For example, poor eye contact, no response to name, or lack of interest in peer interaction would be considered triggers. Information abstracted from records that contained a social behavioral trigger included verbatim developmental histories, descriptions of ASD symptoms, descriptions of co-occurring conditions, results of developmental tests, and documentation of a clinical ASD diagnosis or special education eligibility statement referenced in the record or assigned by the professional who evaluated the child. All abstracted information was combined into one composite record if multiple health/education records were abstracted for the same child. In phase 2, clinician review, clinicians with expertise in diagnosis of ASD reviewed the composite records to determine ASD case status using a coding scheme based on DSM-5 criteria. A child could meet ASD surveillance case definition by having an existing DSM-IV or DSM-5 clinical diagnosis on the autism spectrum. In addition, if a child displayed behaviors from birth through age 8 years on a comprehensive evaluation by a qualified professional that were consistent with the DSM-5 diagnostic criteria for ASD, the child met ASD surveillance case definition. This method allowed for identification of ASD cases even when a formal diagnosis of ASD had not been made. Similarly, clinician reviewers could determine that ASD case status was not met, even in the presence of a formal ASD diagnosis or eligibility, if insufficient information was present to support

ASD case status, or they could overturn ASD case status even if behavioral criteria were met if there was sufficient information that the behaviors were better explained by another diagnosis. Clinician reviewers also provided ratings reflecting certainty of ASD case status, and secondary reviews of records were performed when the primary reviewer's case status certainty was low. Clinicians and abstractors completed training and ongoing reliability checks. Inter-rater agreement on case status (confirmed ASD versus not ASD) was established at 90% and subsequently maintained (k = 0.89; Maenner et al., 2020).

Data Sources

Within each site, children were linked with their birth certificate information from their state to obtain additional demographic information. The Arizona surveillance area included part of one county in metropolitan Phoenix, Georgia included two counties in metropolitan Atlanta, Minnesota included parts of two counties including the cities of Minneapolis and Saint Paul, and North Carolina included four counties in central North Carolina (Maenner et al., 2020).

Variables of Interest

Race and ethnicity were gathered from information abstracted from the medical or education records, which were augmented by data from birth certificates and data from administrative or billing information. Children with race coded as "other" or "multiracial" were excluded from race-specific estimates, as were American Indian/Alaskan Native children due to small numbers (Maenner et al., 2020).

Record source was documented during abstraction and indicated the source in which a developmental evaluation record was found. The specialization/degrees of the evaluators documented on an evaluation report also were recorded (e.g., MD neurologist, Ed.S.). To study the impact of where a child had been evaluated on age of identification, record source was defined as health only (i.e., records for a child were found from health sources only), education only (i.e., records were found from educational sources only), or health and education (records for a child were found from both educational and health sources).

The presence of a formal ASD identification was determined based on (a) having a diagnostic statement from a qualified professional of ASD or (if diagnosed during DSM-IV) autistic disorder, pervasive developmental disorder not otherwise specified, or Asperger disorder; (b) documentation of any ASD ICD billing code at any time from birth through 2016; or (c) receiving (or meeting eligibility for) special education services under the ASD identification in a public school setting. Age of first ASD identification was defined as the age of a child when an examiner recorded an ASD diagnostic or eligibility statement or noted the child's age when another provider previously diagnosed ASD or determined ASD eligibility. Age of first comprehensive evaluation was defined as the earliest documented evaluation for any kind of developmental or behavioral concern, based on each child's abstracted evaluation information and restricted to children born in the state (AZ, GA, NC) or ADDM network surveillance area (MN) (Maenner et al., 2020). Comprehensive evaluations were defined in ADDM as those that were conducted by a professional in a position to evaluate the developmental functioning of children; described the results of

a developmental evaluation; were conducted to identify symptoms, delays, diagnoses, or eligibility classification; consisted of a global assessment of multiple areas or in-depth assessment of one developmental domain (e.g., language, neurology, etc.); and had the purpose of summarizing development or reaching a diagnostic conclusion (ADDM, 2012).

Within educational records, each evaluation was coded to indicate which eligibility category was determined, if any. A specific ASD eligibility code was given if the evaluation resulted in ASD eligibility. DD eligibility was determined based on the child having an eligibility summary statement that indicated (a) the presence of eligibility due to a DD in one or more developmental areas: general or global DDs, cognitive, motor, language, social, or adaptive delays, and (b) the absence of ASD eligibility or any other eligibility category (e.g., Specific Learning Disability, Emotional-Behavioral Disability). Evaluations resulting in DD eligibility in which ASD was considered and ruled out were also excluded from the DD evaluation group, as these evaluations were likely designed to assess for ASD eligibility and not just DD eligibility. This excluded a total of 21 evaluations from analysis.

Intellectual disability (ID) status was assigned when a child's IQ score was ≤ 70 on their most recent IQ test through the end of calendar year 2016, or based on an examiner's statement indicating the presence of ID in a developmental evaluation. IQ data were available for 89% of the sample. The 11% with missing IQ differed from those with IQ on race/ethnicity ($\chi^2 = 17.98$, $p < 0.01$), site ($\chi^2 = 10.11$, $p = 0.02$), and record source ($\chi^2 = 74.47$, $p< 0.01$). A greater proportion of Black children (15%) were missing IQ than White children (9%). Georgia had a greater proportion of children missing IQ (15%) than Arizona (9%), Minnesota (10%), and North Carolina (9%). Finally, children with records only from health sources were more likely to have missing IQ data (31%) compared to children with records from both health and education sources (9%) and from only education sources (8%). No differences were noted by sex.

Level of impairment related to ASD was based on ADDM clinician reviewer ratings assigned based on review of a child's full record, where a rating of 1 indicated mild impairment, 2 indicated moderate impairment, and 3 indicated severe impairment.

During clinician review, reviewers coded the presence of DSM-5 social communication and restricted, repetitive behavior symptoms based on behavioral descriptions documented in the record. DSM-5 symptoms were coded at the evaluation level (i.e., each evaluation report was coded separately for the presence of DSM-5 symptoms). Clinician reviewers were required to maintain inter-rater reliability at the 80% level for coding of DSM-5 symptoms. Clinician reviewers also noted the presence of an ASD measure documented in the record, which included standardized diagnostic measures, checklists or screening measures, as well as site-specific ASD measures (e.g., an interview or observational measure developed by a school district or clinic practice).

Statistical Analyses

For the first objective, records from all source categories were analyzed, and the sample was restricted to those with linkages to birth certificates to ensure that the children lived in the same state as the surveillance area prior to age 8. The four included sites were

compared as to the percentage of children with linked birth certificates, and no statistically significant differences were found. Median age of first ASD identification was calculated for children with a formal identification of ASD as defined above (N = 919). Median age of first comprehensive evaluation was calculated for all children who met ASD surveillance case definition (N = 1139). Median ages were reported to reduce the influence of outliers. Quantile regression (0.5 quantile = median) was used to test the associations of source category (health only, health and education, and education only) and median age of first ASD identification and median age of first comprehensive evaluation, while controlling for site to account for potential differences in availability of ASD services. For all analyses, significance was set a $p < 0.05$.

The second objective analyzed education-only records and compared evaluations of children with ASD eligibility to evaluations of those with DD eligibility. Because each child could have multiple evaluations where symptoms were recorded, evaluations were the unit of analysis. Generalized estimating equations (GEE) were used to account for within-subject and within-site correlation by including cluster statements to account for the covariance between evaluations. To examine whether evaluations resulting in DD eligibility and evaluations resulting in ASD eligibility similarly documented symptoms of ASD, frequencies and percentages were used to describe (a) DSM-5 symptoms present and (b) presence of an ASD measure in evaluations resulting in ASD eligibility compared to DD eligibility. Odds ratios (OR) with confidence intervals (CI) of 95% were used to quantify the magnitude of associations between these elements in ASD versus DD evaluations. Data analyses were performed using SAS version 9.4.

Results

Table 1 includes demographic information by record source. A total of 1493 8-year-old children who met ADDM ASD case status, lived in reporting school districts, came from sites with full access to educational data, and were not missing source of identification were included in the final full sample. The majority of children had records from health and educational sources (N = 998, 67%), followed by education-only (N = 336, 23%) and health-only sources (N = 159, 11 %). The sample was comprised of 81% males and 18% females (1% missing), yielding a male-to-female ratio of 4.5:1.

There were significant differences in the distribution of record source by race/ethnicity, where greater proportions of Black, non-Hispanic children and Asian and Pacific Islander, non-Hispanic children had records from education-only sources compared to White, non-Hispanic children, with a nonsignificant trend for Hispanic children compared to White, non-Hispanic children. A greater proportion of females with ASD had records only from health sources compared to males.

Compared to children without ID, a greater proportion of children with ID had records from health-only or health and education sources versus education-only sources. Compared to children with mild ASD impairment, greater proportions of children with moderate or severe ASD impairment had records from health-only or health and education sources versus education-only sources.

Median Age of Identification

Table 2 displays the results of the comparisons of median age of ASD identification. For the full sample with birth certificate linkages, median age of ASD identification was significantly higher for children with records from education-only sources, with a median age of 69 months compared to 44 months for health-only sources and 50 months for health and education sources ($p < 0.01$). Males with records from education-only sources were identified significantly later (median age of 70 months) than males with records from health-only (44 months) or health and education sources (50 months); females with records from education-only sources were identified later (median age of 63 months) than females with records from health and education sources (49 months). Across each race/ethnicity category, children with records from education-only sources were identified later than children with health and education source records, and this difference was most pronounced for Hispanic children with education-only source records, whose median age of identification was 82 months. White, non-Hispanic children with education-only records were identified later than White, non-Hispanic children with health-only records (median ages of 68 and 39, respectively), and there was a nonsignificant trend in the same direction for Black, non-Hispanic children (median ages of 63 versus 58 months) and Hispanic children (82 versus 38 months). Children without ID with education-only records were identified significantly later (median age of 74 months) than those with health-only or health and education records (56 and 55 months, respectively), and children with ID with education-only records were identified later (median age of 64 months) than those with health-only or health and education (29 and 44 months, respectively) records. Differences were also present for those with mild and moderate ASD impairment, with children with education-only records identified later (median age of 77 and 68 months, respectively) than those with health-only (51 and 39 months) or health and education records (59 and 50 months). No differences in age of first ASD identification were present across record source for children rated with severe impairment.

There were no significant differences in median age of ASD identification documented in records from health-only compared to health and education sources across sex, race/ethnicity, or ID status. Children with moderate ASD impairment with health and education records were identified later (median age 50 months) than children with moderate ASD impairment with health-only records (median age 39 months).

Median Age of First Comprehensive Evaluation

Table 2 displays the results of the comparisons of median age of first comprehensive evaluation. For the full sample with linked birth certificates, median age of first evaluation was significantly later for children with records from education-only sources, with a median age of 53 months compared to 31 months for health-only sources and 35 months for health and education sources. Among both males and females, those with records from education-only sources were evaluated significantly later (median age of 53 months for males and 54 months for females) than those with records from health-only (median ages of 30 and 31 months) or health and education sources (median ages of 36 and 32 months). Across race/ethnicity categories, children with records from education-only sources were evaluated later than children with health and education source records. For White children, Asian children,

and Hispanic children, differences were greatest where those with education-only records were evaluated more than 2 years later than their counterparts with health-only records. White, Asian, and Hispanic children with education-only records also were evaluated later than those with health and education records, with differences ranging from 13 months later (Asian children) to 2 years later (Hispanic children) in education-only records. For Black, non-Hispanic children, median age of first evaluation was not different between those with health-only records and those with education-only records; however, Black, non-Hispanic children with education-only records were evaluated 10 months later than those with health and education records. Children without ID with education-only records were evaluated significantly later (median age of 56 months) than those with health-only (30 months) or health and education (38 months) records, and children with ID with education-only records were evaluated later (median age 46 months) than those with health and education records (32 months). Differences based on level of ASD impairment were also present for those with mild and moderate impairment, with children with mild or moderate impairment with education-only records identified later (median ages of 57 and 52 months, respectively) than those with health-only (34 and 28 months) or health and education (38 and 35 months) records. No statistically significant differences in age of first evaluation were present across record source for children with severe ASD impairment.

There were no significant differences in median age of first comprehensive evaluation documented in records from health-only compared to health and education sources across sex, ID status, or level of impairment. Black, non-Hispanic children with records from health-only sources were evaluated later (median age 50 months) than Black, non-Hispanic children with health and education records (median age 37 months).

ASD Symptoms Documented in Educational Evaluations

A total of 419 evaluations were identified that resulted in a DD eligibility, and 298 evaluations resulted in ASD special education eligibility (Table 3). In the DSM-5 domain of social communication, symptoms falling under the social-emotional reciprocity criterion were less likely to be documented in ASD evaluations compared to DD evaluations (odds ratio [OR] = 0.68, 95% confidence interval [CI]: 0.49–0.94). Females were less likely to have deficits in social-emotional reciprocity documented in ASD evaluations compared to DD evaluations (OR = 0.38, CI: 0.16–0.88) than males (OR = 0.77, 95% CI: 0.55–1.09). There were no significant differences in the presence of symptoms falling under the DSM-5 nonverbal communication criterion or the peer relationships criterion documented in DD compared to ASD evaluations. In the domain of restricted and repetitive behaviors, symptoms from the compulsions/rituals, fixated interests, and unusual sensory responses criteria were documented more frequently in ASD evaluations compared to DD evaluations. The magnitude of the differences was greatest for fixated interests, with an OR of 2.07 (CI: 1.49–2.89). Compulsions/rituals were more likely to be documented in ASD versus DD evaluations (OR = 1.55, CI: 1.11–2.16). Sensory differences were more likely to be documented in ASD evaluations than DD evaluations (OR = 1.63, CI: 1.18–2.25).

Use of an ASD screening or diagnostic measure was more frequent in evaluations resulting in ASD eligibility than for DD eligibility (OR = 3.37, CI: 2.45–4.63), and this magnitude of

association was consistent for males and females and for White, Black, Asian, and Hispanic children (Table 4).

Discussion

This study focused on timing of ASD identification in education versus health settings, including variation by key demographic factors, and the extent to which ASD characteristics are documented in educational evaluations for DD versus ASD eligibility. Educational settings are an important source of ASD identification, as they are by law accessible to all children and not just those with access to healthcare insurance coverage. Further, all states offer Part C services that provide evaluation and early intervention services to children from birth to age 3 years. Despite this access, our study found that children with records from education-only sources received their first comprehensive developmental evaluation and were identified with ASD over a year later than children with records from health sources. The median age of first evaluation for children from education-only sources was over 4 years, compared to under 3 years for children seen in health or health and education sources. This late age of evaluation is inconsistent with evidenced-based practices in early intervention for ASD as well as any DDs, which indicate that interventions provided in sensitive periods of brain development in early childhood can lead to positive outcomes (e.g., Campbell & Ramey, 1994; Dawson et al., 2012). The finding of later age of evaluation also implies that it is not educational eligibility practices and the use of the DD category instead of the ASD category that are delaying ASD identification; children were seen for any kind of evaluation in educational settings later than those seen in health settings.

Later evaluation and later identification in education-only sources was a consistent finding across sex, race/ethnicity, and presence of ID. Children with ID were identified earlier than children without ID across all record sources, but education-only sources were significantly later than health and health and education sources. In addition, Black, non-Hispanic, Asian, and Hispanic children were more likely to have education-only records compared to White, non-Hispanic children, which may suggest disparities in access to evaluations in health settings that might have resulted in earlier identification and intervention. Our findings are consistent with past research that both identified relatively later age of identification in education settings (Pettygrove et al., 2013) as well as lower utilization of health source evaluations for Black children (Yeargin-Allsopp et al., 2003) and Hispanic children (Pettygrove et al., 2013). In our analyses, age of identification and age of first evaluation did not differ for health-only compared to health and education evaluations for most groups, with the exception that Black, non-Hispanic children with health-only records were evaluated later than Black, non-Hispanic children with health and education records. Black children with health-only and educational-only records had similar median age of first evaluation. This finding may suggest that, for Black children in our sample, access to services in both the educational and health systems facilitated earlier evaluation.

An important finding is that 23% of children had evaluations only in an education setting, and since evaluations in most educational settings are for determining “eligibility” for services, rather than a diagnosis (IDEA, 2004), the information conveyed to the parent about their child’s developmental needs may be specific to needs within the education setting.

Further understanding is needed of the information conveyed to families and caregivers regarding the child's needs when an eligibility for services for ASD or DD is conferred as compared to the information shared within a diagnostic evaluation in a health setting. Being identified with ASD through an educational evaluation only also has implications for access to other services. For example, state early intensive behavior intervention services require a medical diagnosis of ASD for access. Thus, the disparities experienced by Black, Hispanic, and Asian children, who were more likely to receive evaluations only in education settings than White children, may compound with less complete diagnostic information shared with families and less access to other available intervention services.

Our study also found that the proportions of children with records from health-only, health and education, and education-only settings differed based on ID status, such that greater proportions of children with ASD with ID were seen in health settings compared to children with ASD without ID. This finding should be interpreted with caution, as records from health-only settings were more likely to be missing ID status than records from education-only and health and education sources. Children with ASD with ID have greater health complexities that may increase the need for contact and evaluation within health settings (e.g., Doshi-Velez et al., 2014; Miles et al., 2005).

In the K-12 educational system, determination of special educational eligibility requires demonstration of educational impact, and it is possible that some children with ASD who do not have language or learning deficits may come to attention later in school or not at all. However, educational impact is not emphasized in Parts C and B, and IDEA requires that educational systems develop and implement "an effective method" to identify, locate, and evaluate children with disabilities, regardless of the severity of their disabilities, starting *from birth* to reduce the need for future services (IDEA, 2004). Our finding that the median age for educational identification occurred over a year later than clinical diagnosis suggests that many systems are not meeting this charge. IDEA further requires Part C systems to coordinate efforts with other state agencies to identify children in need of early intervention, including medical systems. Increased coordination and communication between primary care and early intervention systems is one potential avenue for reducing age of identification and increasing timely intervention (Kogan et al., 2008; Mandell et al., 2005); however, significant barriers remain, including limited time, limited financial and staffing resources, and difficulties sharing information due to privacy issues and the logistical difficulties of obtaining multiple releases of information to share records (Bradley-Klug et al., 2013; Carbone et al., 2010; Shah et al., 2013). Facilitators of care coordination across educational and medical settings include providing training to medical providers on educational systems and vice versa; providing time, support, and resources to facilitate regular meetings to coordinate care; co-location of providers; and dedicating professionals who serve as a point person for families and lead coordination efforts across team members (Doyle, 2008; Shahidullah et al., 2020; Sloper, 2004).

The finding that racial and ethnic minoritized groups have less access to and lower use of ASD services is well documented, and researchers have begun to examine disparities in access to diagnosis and services with the goal of identifying practice recommendations to improve equitable access to care (e.g., Smith et al., 2020). Recommendations include

disseminating information about services in community settings that reach all potential families, providing information in ways that are culturally responsive and in the languages used by families; providing services in locations that present fewer logistical barriers to families; and employing providers who are culturally and linguistically matched to the families they serve (Ault-Brutus & Alegria, 2018; Bender et al., 2013; Pickard & Ingersoll, 2016). Culturally responsive providers build trust between families and professionals, ensure that the identification process is covering the concerns that are most important to families and to their child's goals, and reduce issues of stigma that can prevent families from seeking treatment (Norbury & Sparks, 2013; Smith et al., 2020).

ASD Eligibility Versus Developmental Delay

A common practice for educational evaluations in early childhood is to assess for general developmental disabilities rather than a specific special education category, as it is argued that the categories used for older school-aged children can result in inappropriate categorization or mischaracterization, or that the criteria may be too stringent or specific for the needs of young children, thus resulting in not meeting eligibility and going unserved (Danaher, 2011; Division for Early Childhood, 2009). Another argument is that providing a specific category or "label" to a young child can be stigmatizing, especially for those who respond to early intervention and may not continue to need special education (Danaher, 2011). Previous research is limited on policies and practices across states or school districts in applying DD versus ASD eligibility criteria in young children. In an ADDM Network study examining special education trends from 2002 to 2010, the proportion of children with ASD who had primary eligibility under the DD category increased significantly, from 5.2% in 2002 to 8.1% in 2010 (Rubenstein et al., 2018), indicating that more children who met behavioral criteria for ASD were being served under the noncategorical DD label over time.

Our study examined the coverage of ASD characteristics within reports documenting ASD eligibility versus DD eligibility to understand whether both types of evaluations adequately depict needs related to ASD. This would have important implications from an equity perspective, given the findings that Black, Hispanic, and Asian children were more likely to have been identified only in educational settings. Our study provided some support that an assessment for DD eligibility will cover broad developmental domains affected by ASD and thus provide appropriate representation of the child's needs. We found no statistically significant differences in documentation of DSM-5 nonverbal communication and peer relationship symptoms in evaluations that resulted in DD eligibility compared to evaluations that resulted in ASD eligibility. The DSM-5 criterion of deficits in social-emotional reciprocity was actually documented more frequently in evaluations for DD compared to evaluations for ASD, and this association was strongest for females (OR = 0.38, CI: 0.16–0.88). This finding was surprising given that evaluations for ASD were more likely to include an ASD measure. A possibility is that broad social-emotional measures used in identifying DDs were picking up general deficits in socialization within the DD evaluations, and overall, the differences in documentation of social-emotional reciprocity were small for the full sample (74% versus 70%). A more substantial difference was noted for females versus males, where only 69% of females evaluated for ASD had social-emotional reciprocity symptoms documented compared to 83% of DD evaluations. A close

examination of this question was beyond the scope of this study; however, previous studies have suggested that autism-specific screening measures may disproportionately miss females (Ratto et al., 2018), although this was not shown for social communication symptoms comparing males to females on diagnostic measures (Kaat et al., 2021).

Restricted and repetitive behaviors were less frequently documented in evaluations resulting in DD eligibility compared to ASD eligibility, particularly with regard to compulsions and rituals, fixated interests, and unusual sensory responses. It is reasonable to conclude that this lack of documentation reflects a lack of assessment of these areas of behavior. These areas have been identified as having an impact on overall developmental functioning and well-being (Bishop et al., 2007; Cunningham & Schreibman, 2008), as well as educational functioning (Azad & Mandell, 2016). Increases in flexibility and reductions in repetitive behaviors that are distracting or impairing are common treatment goals in early intervention (Boyd et al., 2011, 2012; Grahame et al., 2015; Lin & Koegel, 2018; Rapp & Vollmer, 2005) and are likely to have relevance for early learning and early school-age environments. Similarly, a specific ASD measure was less often used in evaluations resulting in DD eligibility. This finding is not surprising, as ASD may not have been the specific referral question for many of these evaluations. However, an ASD measure is more likely to identify needs related to restricted and repetitive behaviors than measures of general development.

Although not a focus of the current study, we found that a specific ASD measure was used in just over half of evaluations resulting in ASD eligibility, which is troubling given the recommendations for use of valid and reliable diagnostic measures for ASD to increase accuracy of decision-making (Esler & Ruble, 2015). Future research using ADDM data could look at overall evaluation quality and the components or tests included in evaluations.

Limitations

Our study has several limitations. First, ADDM Network methods are based on record review and dependent on quality and completeness of existing documents. Restricted access to records, incomplete records, or both could lead to inaccuracies in estimating timing of ASD identification, timing of first comprehensive evaluation, and when and how ASD was specifically assessed. Data were collected through review of records available in the sources included in ADDM's surveillance area, and it is possible that children in the education-only group were seen in health sources outside of the surveillance area, or vice versa, which might impact the findings. We did not separately identify and analyze age of first *special education* ASD identification in children who had records from health and education sources, so this analysis does not address whether these children were identified earlier in schools (i.e., eligible under the ASD category) as well as in health sources compared to children with education-only records. Second, because of the way the ADDM Network documents record source, some records located in education sources may have been external reports shared from health sources, and vice versa. Third, our data were limited to the information documented within records, and we may not have had access to key information leading to decisions about whether to evaluate for the DD category versus the ASD category. Special education evaluation decisions are team decisions, where parent input is an important component. Parents may not have agreed to evaluate specifically for

ASD even when the educational team felt it was appropriate to do so. Fourth, because ADDM methodology gathers data through review of evaluation reports, children who lacked access to evaluation services would have been excluded due to insufficient documentation for ASD case determination (Imm et al., 2019). Finally, sites participating in the ADDM Network are not nationally representative, and our data relied on a subset of ADDM sites with full access to educational records and consistent documentation of record source. Sample sizes were small for some comparisons, leading to imprecise estimates.

Implications

Educational settings are an important source of early intervention so identifying ways to reduce age of evaluation and age of identification in these settings may be relatively more accessible to culturally and socioeconomically diverse groups (Yeargin-Allsopp et al., 2003). Future research could identify where the delays are occurring, and if they are a result of delays in screening and referral in pediatric wellchild settings, public health screening, early childhood screening, or all of the above. At the same time, future research could explore how universal access to health evaluations for developmental concerns, including ASD, improves outcomes.

Our study also provides evidence that evaluations for DD eligibility may not fully capture the needs of students with ASD. In 2009, the Division for Early Childhood (DEC) of the Council for Exception Children (https://www.decdocs.org/concept-paper-developmental-delay) made recommendations for the use of the DD eligibility category and when to consider and assign specific disability eligibility criteria rather than the DD category. They specifically cautioned that children with “low incidence, multiple, or significant disabilities,” including ASD, are at-risk for loss of services, inappropriate services, lack of access to qualified service providers, or inadequate or inappropriate funding resources as they require specialized interventions to meet their needs (DEC, 2009, pp. 2–3). Our findings support that ASD-specific evaluations capture relevant autism-related behaviors that can inform a child’s address important needs for intervention planning.

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Table 1

Demographics of children aged 8 years with autism spectrum disorder (ASD) based on Source of Records Reviewed, Autism and Developmental Disabilities Monitoring Network, Study Year 2016

	Records from health sources only		Records from health and education sources		Records from education sources only		p value
	N	Row %	N	Row %	N	Row %	
All[a]	159	11	998	67	336	23	< .01
Sex							
Male	114	9	831	68	276	23	Ref
Female[a,b]	45	17	167	61	60	22	0.02
Race/Ethnicity							
White, Non-Hispanic	87	14	430	67	126	20	Ref
Black, Non-Hispanic[a,b,c]	38	9	262	65	101	25	< .01
Asian or Pacific Islander, Non-Hispanic[b]	9	7	85	68	31	25	0.05
Hispanic, regardless of Race[b]	19	8	168	69	57	23	0.06
Presence of intellectual disability							
No	56	6	597	67	238	27	Ref
Yes[b,c,d]	53	12	313	72	70	16	< .01
Missing[a,b]	50	30	88	53	28	17	< .01
Level of impairment associated with ASD							
Mild	62	10	361	61	170	29	Ref
Moderate[c]	74	11	487	69	140	20	< .01
Severe[b,c]	23	12	150	75	26	13	< .01

Ref referent

[a] $p < 0.05$ for health only and health and education records

[b] $p < 0.05$ for health only and education only records

[c] $p < 0.05$ for health and education and education only

[d] Defined as IQ ≤ 70 or an examiner's statement indicating the presence of intellectual disability

Table 2

Age of autism spectrum disorder identification and age of first comprehensive evaluation by record Source, Autism and Developmental Disabilities Monitoring Network, Study Year 2016

	Age in months of first ASD identification[a]						p value	Age in months of first comprehensive evaluation[a]						p value
	Records from health sources only		Records from health and education sources		Records from education sources only			Records from health sources only		Records from health and education sources		Records from education sources only		
	N	Median	N	Median	N	Median		N	Median	N	Median	N	Median	
All[b,c]	69	44	687	50	163	69	< .01	125	31	757	35	257	53	< .01
Sex														
Male[b,c]	48	44	587	50	137	70	< .01	87	30	643	36	211	53	< .01
Female[b,c]	21	47	100	49	26	63	< .01	38	31	114	32	46	54	< .01
Race/Ethnicity														
White, Non-Hispanic[b,c]	40	39	293	53	60	68	< .01	76	28	321	34	95	55	< .01
Black, Non-Hispanic[c,d]	18	58	172	49	45	63	< .01	25	50	194	37	76	47	< .01
Asian or Pacific Islander, Non-Hispanic[b,c]	2	31	55	49	15	64	< .01	5	21	60	39	22	52	< .01
Hispanic, regardless of race[b,c]	7	38	129	51	35	82	< .01	16	29	139	37	47	61	< .01
Presence of ID														
No[b,c]	23	56	395	55	106	74	< .01	44	30	444	38	175	56	< .01
Yes[c,e]	20	29	232	44	37	64	< .01	43	25	248	32	59	46	< .01
Missing[b,c]	26	47	60	44	20	54	.06	38	42	65	41	23	53	.09
Level of impairment associated with ASD														
Mild[b,c]	19	51	220	59	65	77	< .01	50	34	271	38	128	57	< .01
Moderate[b,c]	36	39	355	50	84	68	< .01	59	28	372	35	110	52	< .01
Severe	14	47	112	39	14	51	.16	16	30	114	33	19	46	.46

[a] Restricted to children with a linked birth certificate to indicate that they were born in state

[b] $p < 0.05$ for health only and education only records

[c] $p < 0.05$ for health and education and education only records

[d] $p < 0.05$ for health only and health and education

[e] Defined as IQ≤70 or an examiner's statement indicating the presence of intellectual disability

Table 3

Documentation of diagnostic and statistical manual-5th edition (DSM-5) Autism Spectrum Disorder (ASD) symptom exemplars in educational evaluations resulting in developmental delay eligibility and ASD eligibility, autism and developmental disabilities monitoring network, study year 2016

	Developmental delay eligibility		ASD eligibility		Odds ratio[a]	95% CI	p value
	N	Symptom present (%)	N	Symptom present (%)			
Total educational evaluations							
All	419		298				
Sex							
Male	341		247				
Female	78		51				
Race/Ethnicity							
White, Non-Hispanic	142		113				
Black, Non-Hispanic	135		87				
Asian or Pacific, Non-Hispanic Islander	40		31				
Hispanic, regardless of Race	77		54				
DSM-5 diagnostic criteria documented in evaluation social-emotional reciprocity criterion							
All	308	74	208	70	0.68	0.49–0.94	0.02
Sex							
Male	243	71	173	70	0.77	0.55–1.09	0.15
Female	65	83	35	69	0.38	0.16–0.88	0.02
Race/Ethnicity							
White, Non-Hispanic	106	75	84	74	0.87	0.50–1.51	0.62
Black, Non-Hispanic	97	72	60	69	0.57	0.31–1.06	0.08
Asian or Pacific Islander, Non-Hispanic	31	78	21	68	0.48	0.21–1.08	0.08
Hispanic, regardless of Race	54	70	35	65	0.92	0.46–1.87	0.83
Nonverbal communication criterion							
All	238	57	190	64	1.21	0.88–1.66	0.24
Sex							
Male	190	56	158	64	1.29	0.91–1.85	0.16
Female	48	62	32	63	0.90	0.47–1.76	0.77

	Developmental delay eligibility		ASD eligibility		Odds ratio[a]	95% CI	p value
	N	Symptom present (%)	N	Symptom present (%)			
Race/Ethnicity							
White, Non-Hispanic	83	58	77	68	1.49	0.89–2.50	0.13
Black, Non-Hispanic	75	56	56	64	1.12	0.63–2.01	0.70
Asian or Pacific Islander	24	60	16	52	0.57	0.24–1.33	0.19
Hispanic, regardless of race	45	58	33	61	1.37	0.62–3.02	0.44
Peer relationships criterion							
All	264	63	194	65	0.96	0.69–1.32	0.78
Sex							
Male	214	63	162	66	0.99	0.69–1.42	0.96
Female	50	64	32	63	0.80	0.40–1.63	0.54
Race/Ethnicity							
White, Non-Hispanic	92	65	78	69	1.14	0.66–1.97	0.64
Black, Non-Hispanic	87	64	55	63	0.63	0.35–1.15	0.13
Asian or Pacific Islander	22	55	21	68	1.43	0.66–3.13	0.37
Hispanic, regardless of race	45	58	31	57	1.11	0.52–2.37	0.79
Repetitive actions, speech, motor movements criterion							
All	238	57	191	64	1.22	0.89–1.67	0.22
Sex							
Male	192	56	160	65	1.30	0.92–1.84	0.14
Female	46	59	31	61	0.94	0.44–2.01	0.87
Race/Ethnicity							
White, Non-Hispanic	86	61	71	63	1.02	0.61–1.71	0.94
Black, Non-Hispanic	75	56	58	67	1.23	0.66–2.26	0.51
Asian or Pacific Islander, Non-Hispanic	21	53	20	65	1.21	0.53–2.77	0.65
Hispanic, regardless of Race	44	57	34	63	1.67	0.77–3.62	0.20
Compulsions/Rituals criterion							
All	183	44	167	56	1.55	1.11–2.16	0.01
Sex							
Male	149	44	138	56	1.54	1.07–2.22	0.02

	Developmental delay eligibility		ASD eligibility		Odds ratio[a]	95% CI	p value
	N	Symptom present (%)	N	Symptom present (%)			
Female	34	44	29	57	1.56	0.70–3.47	0.28
Race/Ethnicity							
White, Non-Hispanic	62	44	70	62	2.12	1.21–3.71	< 0.01
Black, Non-Hispanic	65	48	45	52	1.03	0.57–1.86	0.92
Asian or Pacific Islander	13	33	16	52	1.79	0.75–4.27	0.19
Hispanic, regardless of Race	35	45	30	56	1.75	0.78–3.96	0.18
Fixated interests criterion							
All	123	29	141	47	2.07	1.49–2.89	< 0.01
Sex							
Male	102	30	118	48	2.06	1.43–2.97	< 0.01
Female	21	27	23	45	2.05	0.92–4.59	0.08
Race/Ethnicity							
White, Non-Hispanic	45	32	61	54	2.61	1.58–4.33	< 0.01
Black, Non-Hispanic	44	33	46	53	1.98	1.03–3.78	0.04
Asian or Pacific Islander	11	28	11	35	1.31	0.46–3.69	0.62
Hispanic, regardless of race	20	26	20	37	1.84	0.80–4.25	0.15
Sensory criterion							
All	194	46	178	60	1.63	1.18–2.25	< 0.01
Sex							
Male	154	45	148	60	1.73	1.21–2.48	< 0.01
Female	40	51	30	59	1.24	0.60–2.58	0.56
Race/Ethnicity							
White, Non-Hispanic	67	47	72	64	2.00	1.20–3.36	< 0.01
Black, Non-Hispanic	64	47	51	59	1.33	0.73–2.41	0.36
Asian or Pacific Islander, Non-Hispanic	18	45	16	52	1.33	0.49–3.56	0.57
Hispanic, regardless of race	36	47	32	59	1.87	0.84–4.16	0.12

CI confidence interval

[a] Calculation of odds ratios used developmental disability as the referent group

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Table 4

Use of an autism spectrum disorder (ASD) assessment measure in evaluations for developmental delay (DD) eligibility and autism spectrum disorder eligibility, autism and developmental disabilities monitoring network, study year 2016

ASD measure used	Eligibility						
	DD		ASD				
	N	%	N	%	Odds Ratio [a]	95% CI	p value
All	100	24	153	52	3.37	2.45–4.63	< .01
Sex							
Male	82	24	124	50	3.18	2.24–4.53	< .01
Female	18	23	29	57	4.39	2.05–9.44	< .01
Race/Ethnicity							
White, Non-Hispanic	32	23	57	50	3.50	2.04–6.00	< .01
Black, Non-Hispanic	39	29	48	55	3.03	1.73–5.32	< .01
Asian or Pacific Islander	7	18	14	45	3.88	1.32–11.43	.01
Hispanic, regardless of Race	20	26	30	56	3.56	1.70–7.47	< .01

CI confidence interval

[a]Calculation of odds ratios used developmental disability as the referent group