Late Diagnosis of Autism Spectrum Disorder After Initial Negative Assessment by a Multidisciplinary Team

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Late Diagnosis of Autism Spectrum Disorder After Initial Negative Assessment by a Multidisciplinary Team

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ABSTRACT: *Objective:* Describe a cohort of children who received a diagnosis of autism spectrum disorder (ASD) after age 6 and after having undergone a comprehensive multidisciplinary assessment before the age of 6, through which they were not diagnosed with ASD. *Methods:* Extensive chart review of patients' electronic medical records comprised a representative population-based registry of patients seen during 2004 to 2011. The study focused only on the cohort of children who were diagnosed with ASD after the age of 6 but were not diagnosed with ASD at an earlier age. The charts were reviewed for the number of developmental assessments completed and the clinician's diagnostic impressions. The charts were also examined for documentation of ASD-suggestive features pulled directly from the text of the evaluators' reports. *Results:* A total of 221 patients (189 males) were diagnosed with ASD after age 6 although their initial comprehensive developmental evaluations before the age of 6 were negative for ASD. The study cohort underwent a total of 1028 developmental evaluations before the age of 6, with initial diagnostic impressions that included language deficits (70%), motor difficulties (67%), attention problems (46%), and cognitive difficulties (42%). Less than half of the cohort had ASD-suggesting features documented in their initial assessment. *Conclusions:* Subsequent late diagnosis of ASD after an initial ASD-negative comprehensive assessment is a common clinical experience. Reasons for this scenario may include evolving diagnosis as well as missed and overdiagnosed cases of ASD.

(J Dev Behav Pediatr 00:1–8, 2015) **Index terms:** autism, autism spectrum disorder, diagnosis, diagnostic evaluation, late diagnosis.

Although autism spectrum disorders (ASD) are well known, many children are still diagnosed relatively late.[1] There are several reported reasons for late diagnosis. In a comprehensive review of 42 studies published in the last 20 years, several categories of reasons have been identified for delay in ASD diagnosis, including clinic characteristics, sociodemographic characteristics, level of parental concern about a developmental problem in their child, systems interactions, and geographic region.[2] The most consistent findings were that children with autism tended to be diagnosed at younger ages than children with Asperger Syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (presumably because of lack of language delay and/or milder features in the latter 2 diagnoses), and that the age of

diagnosis is decreasing over time. Additionally, children with greater symptom severity tended to be diagnosed earlier, as did children from families of higher socioeconomic status and with greater parental concern. Findings were mixed regarding other factors, including the presence of cognitive impairment, race and ethnicity factors, and community wealth. Delay in diagnosis has also been explained by various factors, such as inadequate screening practices, inappropriate or delayed responses of physicians to parental concerns, low sensitivity of screening instruments for autism, and a general lack of awareness of autistic symptoms.[3] Diagnosis may also be delayed due to the presence of other developmental concerns, particularly those for which there is symptom overlap with ASD, such as specific language impairment, global developmental delay, and attention-deficit hyperactivity disorder.[4,5] There may also be increased incentives at a later age for the diagnosis of ASD, as an ASD diagnosis is often required for, or tied to, specific interventions or services.[6,7] One study found an association between late diagnosis of ASD and the number and severity of autistic behavioral features, such problems developing peer relations, impaired conversational abilities, and idiosyncratic speech.[8] In a US study, Hispanic and African-American children were more likely than white children to receive an ASD diagnosis after age 4 years.[1]

In some cases, ASD diagnoses may be assigned to older children who had previously undergone comprehensive

developmental assessments at younger ages, through which an ASD diagnosis was not assigned, although there are fewer studies of this type. The issue of later ASD diagnoses in children who underwent comprehensive developmental assessments at young ages is especially intriguing and different from the issue of children who simply receive an ASD diagnosis at an older age without having been previously assessed. In the former scenario, these are children who presumably had developmental concerns, including possibly ASD, yet ASD was not diagnosed until they were assessed at an older age.

In one study, Jónsdóttir et al[9] compared an early ASD diagnosis group (58 children diagnosed before the age of 6) with a late ASD diagnosis group (48 children diagnosed after age 6). Half of the late diagnosis group (compared with 14% in the early group) received a different developmental diagnosis before their ASD diagnosis, with language disorder as the leading diagnosis.

In this study, we aim to characterize and describe a cohort of children who underwent comprehensive developmental assessments from infancy through the age of 6 and were not found to have ASD but received an ASD diagnosis over age 6 in a different clinical setting. Specifically, we reviewed children's early medical records for medical findings, diagnostic impressions, and mention of autistic features. In contrast to studies comparing children who receive early versus late ASD diagnosis, this study seeks to describe a unique but not rare group of children who received an ASD diagnosis later despite early comprehensive developmental evaluation through which ASD was not diagnosed. With careful analysis of the initial diagnostic process and findings through which ASD was not diagnosed, we aim to use this descriptive case series to better understand late diagnosis of ASD and suggest reasons for later assignment of an ASD diagnosis in children previously evaluated.

METHODS
Procedure

Israel has a socialized health care system in which all citizens are free to choose from among 4 health maintenance organizations. Patient fees are equivalent across all 4 HMOs, and all HMOs provide equivalent medical services that are based on national health regulations. For this review, we examined data on autism spectrum disorder (ASD) diagnoses from the computer database of the second largest HMO, Maccabi Healthcare Services, which provides services to 1.94 million people, or 25% of the Israeli population.[10] Of those registered in Maccabi Healthcare Services, approximately 30% are children were 15 years old or younger.

In Maccabi Healthcare Services, for children up to the age of 6 years, concerns about developmental difficulties including ASD are typically raised by parents, preschool teachers, or the primary pediatrician. Concerns can also be raised by nurses and physicians in the family health clinic, where infants receive routine health checkups,

immunizations, and developmental screenings. All concerns are directed to the child's primary pediatrician, who refers the child to a Maccabi Child Development Center (MCDC) or a similar hospital-based center for a thorough developmental evaluation. At the MCDC, a physician specialist in pediatric neurology and child development examines the child, assesses general development, and determines which additional evaluations the child requires (e.g., psychological or speech and language). In more complex cases (children with more than 1 area of delay), there is often a multidisciplinary team meeting, where members work together to arrive at a diagnostic conclusion and plan treatment options.

For children aged 6 and above, concerns about communication problems are usually raised by parents or teachers. Children are then referred to pediatric neurologists or child psychiatrists, who evaluate children in their offices and make diagnoses. Since 2008, children accessing government benefits for ASD must be diagnosed by both a physician and a child psychologist. Both the psychologist and pediatric neurologist/child psychiatrist must make their diagnosis of ASD based on the DSM-4 criteria.[11]

Case Identification

With approval from the Ethics Review Board of Maccabi Healthcare Services, a search of Maccabi Healthcare Services computerized database was conducted for the 2004 to 2011 period for all children's ASD diagnoses that were noted by a Maccabi physician. We excluded all ASD diagnoses given to children before the age of 6 and focused only on late ASD diagnoses, which we defined as being made over the age of 6 and up through the age of 12. We chose 6 as the early cutoff age, because until that time, children with developmental difficulties are closely followed by the MCDC team. The age of 12 was chosen as the late cutoff age, because at that age, we could ensure that we had Maccabi's complete computerized charts for all children. Two authors (M.D. and D.G.) reviewed charts, verified the ASD diagnosis, and that it was made over the age of 6 years. The late diagnosis was further categorized by the type of professional who made the diagnosis (neurologist or psychiatrist) and where the diagnosis was made. If the ASD diagnosis was made inside Maccabi, this information was part of the electronic medical record (EMR) and able to be viewed by the first author. If the diagnosis was made outside of Maccabi, M.D. and D.G. were able to see the primary pediatrician's note of the diagnosis and its source (e.g., hospital or private setting). It should be noted that the same diagnostic criteria for ASD are required both inside and outside of Maccabi. We were not able to subcategorize children by diagnoses of Autism, Asperger Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified as clinicians did not routinely use this diagnostic terminology. In addition, after ASD diagnosis is made externally to MCDC, for children to receive ASD-related services through Maccabi, parents

must present a valid ASD evaluation including physician and psychologist components, which is entered into the EMR. Measures of socioeconomic status (SES) were made based on a scale that divides geographic locations into different socioeconomic categories on a scale ranging from 1 to 10, where 1 is the lowest SES and 10 is the highest (Israeli Central Bureau of statistics determine SES based on multiple factors, such as age of residents, number of new immigrants, recipients of income supplement and unemployment, and not income).[12] We assigned each individual a number based on his reported residence, and for the purposes of our analysis, divided the figures into low SES (1-4 level), average SES (5-6), high average SES (7-8), and high SES (9-10) groups.

We then focused on the cohort of children who received a late ASD diagnosis and who had been evaluated in the MCDC before the age of 6. Their MCDC charts were reviewed by the 2 authors (M.D., D.G.) for all previous diagnoses assigned at the assessments performed before age of 6 at the MCDC. Clinician diagnostic impressions were culled from diagnoses lists (e.g., DSM-4 diagnoses) and from chart summaries. All diagnostic impressions were coded and then collapsed into 9 meaningful clusters, based on the clinical judgment of 2 authors as a result of their review of the clinical chart: motor, language, cognitive, behavior, emotional, attention, regulatory, communication (Table 1), and medical findings (Table 2). Diagnostic impressions were further compared by type of professional (physician specialist in child neurology and development, occupational therapist, psychologist, and speech and language pathologist) who made the diagnosis. If a child had multiple diagnostic impressions, then all of these impressions were coded.

We next reviewed children's charts for the presence of ASD features in their MCDC evaluations before the age of 6. These features were pulled directly from the text of the evaluators' reports, usually from the behavioral impressions or summary sections. All ASD features were coded and collapsed into meaningful categories aligned with DSM-4 criteria for ASD: Cluster A reflected social interaction concerns, Cluster B reflected communication concerns, and Cluster C reflected restricted and repetitive behaviors (Table 3). Additionally, the cohort was divided into 2 groups: the first consisted of children for whom no ASD features were documented before the age of 6 years (No Early ASD Features Group), and the second consisted of children in which ASD-suggestive features were documented before the age of 6 years (Positive ASD Features Group). Further comparisons were made according to the type of professional (physician specialist in child neurology and development, occupational therapist, psychologist, and speech and language pathologist) who documented the ASD-suggestive features. No Early ASD Features Group and Positive ASD Features Group variables were also compared using χ^2 analysis.

RESULTS
Case Identification

Inclusion criteria for case identification were children with diagnosis of autism spectrum disorder (ASD) between ages 6 and 12 and evaluation through Maccabi Child Development Center (MCDC) before age 6. The computer search of Maccabi Healthcare Service's registry resulted in 2867 children who received an ASD diagnosis from a physician between 2004 and 2011. The search yielded definitive diagnoses and physicians' comments regarding suspected cases of ASD. We excluded 2120 children who were diagnosed with ASD before the age of 6. Two authors (M.D. and D.G.) reviewed the remaining 747

Table 1. Clinician Diagnostic Impressions Before Age 6

Cluster	Motor	Language	Cognitive	Behavior
	Fine motor and visual motor deficits	Receptive and or expressive language deficit	Learning disability	Behavior problems
	Gross motor deficits	Dyspraxia	Intellectual deficits	Oppositional defiant behavior
	Developmental coordination disorder[11]		Low normal/borderline IQ	
			Global delay	
			Nonverbal Learning Disability	

Emotional	Attention	Regulatory	Communication
Anxiety	Attention and or hyperactivity	Sleeping problems	Communication problems
Selective mutism		Eating problems	Pragmatic difficulties
		Sensory regulatory problems	Social deficits
			Multisystem developmental disorder[13]

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Table 2. Medical Findings Cluster and Number/Percentage of Children Identified by the Physicians Before Age 6

Medical Findings	Number (%) of Children, n = 212
Hypotonia	17 (7.7)
Preterm	11 (5)
Dysmorphic features or Congenital anomalies	9 (4.1)
Cerebral palsy	6 (2.7)
Epilepsy	5 (2.3)
Microcephaly	5 (2.3)
Hypertonia	4 (1.8)
Laxity of ligaments	2 (0.9)
Macrocephaly	1 (0.5)
Hydrocephalus	1 (0.5)
Fragile X	1 (0.5)
Perinatal brain damage	1 (0.5)
Congenital hypothyroidism	1 (0.5)
Congenital infection	1 (0.5)

charts, with an agreement between raters of 95%. An additional 202 children were excluded because they were determined to have been diagnosed before the age of 6 (despite being registered otherwise), and another 182 children were excluded because there were no sufficient information regarding the exact date of the diagnosis or there was a diagnosis of suspicion of ASD. The remaining 363 children were diagnosed between ages 6 and 12. Of the 363 children, 142 children (124 male, 87%) had no record of a previous MCDC evaluation and 221 children (189 male, 85%) had been previously evaluated through the age of 6 at MCDC. These 221 children comprised our cohort.

Case Description

The cohort was further characterized: the average age of ASD diagnosis was 8 years 4 months (SD, 1 year 10 months). The number of children receiving an ASD diagnosis older than 6 years increased during the time period studied (2004–2011), with 17% being diagnosed between 2004 and 2007, and 83% diagnosed between 2008 and 2011. ASD diagnoses were assigned to 38% of children within the Maccabi system by either a child neurologist or psychiatrist and 38% in a private or hospital setting by either a child neurologist or psychiatrist. For the remaining 24%, although there was an ASD diagnosis entered into the electronic medical record (EMR) by the primary physician, there were no sufficient information to determine the source of the diagnosis.

At the MCDC, children could be seen by a number of professionals, including physician specialists in child neurology and development, occupational therapists, psychologists, and speech language pathologists. Most children (78%) were evaluated by 2 to 4 professionals, most often by a physician specialist in child neurology and development along with at least 1 other professional. A single professional, usually a physician, evaluated the remaining 22% of children. In these cases, the physician completed a developmental assessment and determined that further assessment or follow-up was not warranted. Among the 221 children, the total number of evaluations made by professionals was 1028 with a mean of 4.7 evaluations per child (Table 4). The average age of children across all MCDC evaluations was 3 years 8 months (SD, 1 year 6 months). The average age of first MCDC diagnosis was 3 years 3 months, and the average time between the first MCDC diagnosis and ASD diagnosis was 5 years and 1 month. Regarding SES, 10% of children were in the low SES group, 27.5% were in the

Table 3. Reported Autistic Feature Clusters Based on DSM-4 Criteria of Autism Spectrum Disorder Before Age 6

Cluster A—Social Interaction Concerns	Cluster B—Communication Concerns	Cluster C—Restricted and Repetitive Behaviors
Abnormal eye contact	Communication regression	Attraction to spinning objects
Deficits in the theory of mind	Does not respond to name	Difficulty adjusting to changes
Does not point	Echolalia	Fixations/obsessions
Inappropriate interest in people	Hyperlexia	Inflexibility
Inappropriate joint attention	Inappropriate symbolic play	Repetitive behavior
Inappropriate social interaction and understanding of social situation	Pragmatic deficits	Stereotypic movements
Limited range of affect	Repetitive speech	Rituals
Inappropriate understanding of feelings	Unusual language	Sensory abnormalities
Living in his/her own world	Unusual voice quality	Tiptoe walking
Less or no gestures		Unusual pattern of thinking
Low tendency for communication		
Unusual engagement with adults		

average SES group, 27.5% were in the high average SES group, and 35% were in the high SES group.

Diagnostic Impressions and Autistic Features

Overall, the most common initial diagnostic impressions in the cohort were language deficits (70%), motor difficulties (67%) attention problems (46%), and cognitive difficulties (42%). Medical diagnoses were reported in 24% of the children, with the most frequently reported being hypotonia and preterm history (Table 2). Table 5 contains a breakdown of all diagnostic impressions by the type of professional.

In the cohort, 128 (57.9%; No Early ASD Features Group) had no ASD-suggestive features documented in their charts, whereas the remaining 93 (42.1%; Positive ASD Features Group) did have documented ASD features before the age of 6. Although the same percentage of children in both groups was seen by a physician, more children in Positive ASD Features Group were evaluated by other specialists (Table 4). In particular, more children in Positive ASD Features Group underwent psychological evaluation, relative to No Early ASD Features Group, and this was statistically significant ($\chi^2 = 3.94$; $p = .047$). In Positive ASD Features Group, 88% of children were seen by multiple team members (56% seen by 3 or more team members) versus 70% in No Early ASD Features Group (37% seen by 3 or more team members). In 39 children (42% of Positive ASD Features Group or 18% of the cohort), the possibility of an ASD diagnosis was explicitly considered, and then rejected, either by a physician specialist in Child Neurology and Development or at a team meeting.

We further characterized the type of ASD features noted for children in Positive ASD Features Group. Positive ASD Features Group had a total of 491 evaluations (a mean of 5.2 per child) and ASD-suggestive features were documented in 212 (43%) of these professional evaluations. The total number of autistic features noted by all professionals was 390 (a mean of 4.2 per child).

Social interaction concerns (Cluster A) were noted by all professionals in 78% of children in Positive ASD Features Group. The most commonly noted features in this cluster were "inappropriate social interaction" and "abnormal eye contact." Communications concerns (Cluster B) were noted by all professionals in 41% of children, with the most commonly noted features in this cluster being "pragmatic deficits" and "echolalia." Restricted and repetitive behaviors (Cluster C) were noted in 49% of children, with the most commonly noted features being "repetitive behaviors" and "inflexibility." The most frequent diagnostic impressions for Positive ASD Features Group, as noted by physicians, were language deficits (present in 71% of children as compared with 47% in No Early ASD Features Group) and motor difficulties (present in 49% of children vs 57% in No Early ASD Features Group).

Of children receiving late diagnosis of ASD, 61.9% had further confirmation of ASD diagnosis based on EMR documentation that the child was receiving ASD treatment services through Maccabi. Recall that to receive ASD treatment services in Maccabi, both physician and psychologist documentation of DSM-4 criteria for ASD must be present and reviewed to permit access to ASD treatment. Therefore, in the group of late diagnosis children, 61.9% went on to have their ASD diagnosis confirmed (No Early ASD Features Group, 60.9% and Positive ASD Features Group, 63.4%). For the remaining 38.1%, there is no information about whether this group sought ASD treatment services, and the diagnosis was not confirmed.

DISCUSSION

This study describes a large subgroup of children who received a diagnosis of autism spectrum disorder (ASD) after age 6, having been previously comprehensively evaluated before the age of 6 and not receiving an ASD diagnosis. We found that although the children in our cohort received a diagnosis of ASD later in life, 57.9% did

Table 4. Number of Children Tested Before Age 6 by Team Members and Number of Evaluations

	Physician	Psychologist	Occupational Therapist	Speech/ Language Pathologist	Total
Total number of children tested by each professional: No Early ASD Features Group (n = 128, 100%)	123 (96%)	48 (38%)	61 (48%)	46 (36%)	
Total number of children tested by each professional: Positive ASD Features Group (n = 93, 100%)	89 (96%)	56 (60%)[a]	51 (55%)	49 (53%)	
Total number of children tested by each professional	212 (96%)	104 (47%)	112 (51%)	95 (43%)	
Number of evaluations by each professional: No Early ASD Features Group (mean number of evaluations per child)	332 (2.7)	64 (1.3)	84 (1.4)	57 (1.2)	537 (4.2)
Number of evaluations by each professional: Positive ASD Features Group (mean number of evaluations per child)	264 (3)	80 (1.4)	73 (1.4)	74 (1.5)	491 (5.3)
Total Number of evaluations by each professional (mean number of evaluations per child)	596 (2.8)	144 (1.4)	157 (1.4)	131 (1.4)	1028 (4.7)

The cohort comprised N = 221 (100%) children in the early child development center assessment. [a]Significant difference ($\chi^2 = 3.94$, $p = .047$).

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Table 5. Diagnostic Impression Distribution Before Age 6: Total Cohort and by Child Development Center Clinicians

Diagnosis Impression	Physician (N = 212, 100%)	Psychologist (N = 104, 100%)	OT (N = 112, 100%)	SLP (N = 95, 100%)	Total (N = 221, 100%)
Language	**121 (57%)**	**47 (45%)**	21 (19%)	**87 (92%)**	**155 (70%)**
Motor	**114 (54%)**	22 (21%)	**76 (68%)**	2 (2%)	**148 (67%)**
Attention	**77 (36%)**	**36 (35%)**	**30 (27%)**	**14 (15%)**	102 (46%)
Cognitive	68 (32%)	**50 (48%)**	9 (8%)	6 (6%)	93 (42%)
Behavior	57 (27%)	5 (5%)	15 (13%)	**9 (9%)**	65 (29%)
Medical	52 (25%)	3 (3%)	2 (2%)	1 (1%)	53 (24%)
Regulatory	27 (13%)	8 (8%)	**24 (21%)**	3 (3%)	48 (22%)
Communication	26 (12%)	11 (11%)	2 (2%)	6 (6%)	32 (14%)
Emotional	16 (8%)	8 (8%)	1 (1%)	0	22 (10%)

The 3 main diagnostic impression of each clinician are formatted bold. OT, occupational therapist; SLP, speech/language therapist.

not have any ASD-suggestive features noted in their initial professional evaluations at a Maccabi Child Development Center (MCDC). A subset of the children (Positive ASD Features Group) had some documented ASD-suggestive features in their initial evaluations, but these were documented in less than half of their assessments.

Gillberg has suggested that there may be delay to final developmental disability diagnosis, including ASD, when children are seen by a single health care professional.[14] However, in our sample, 78% of the cohort was evaluated at an early age by 2 or more developmental team members. These evaluations were often made repeatedly over a period of several years.

In contrast to other studies identifying low socioeconomic status (SES) as a risk factor for late diagnosis, this group of children had high SES, with 90% in average, high average, or high SES range. It must be noted that this group of children differs from other studies of late ASD diagnosis because these children were not simply late to ASD diagnosis but received an ASD diagnosis After an initial ASD-negative evaluation. In this study, 35% of ASD cases diagnosed after 6 years old were in the highest SES category, whereas in a recent Israeli ASD prevalence study[15] of children with ASD from ages 1 to 12 including the majority of this cohort, only 2% of children with ASD were in the highest SES level. SES distribution comparison for the remaining cohort of this study, compared with previous epidemiologic data was 10% versus 14% for 1 to 4 level, 27.5% versus 28% for 5 to 6 level, and 27.5% versus 56% for 7 to 8 level. This raises the question of whether a late ASD diagnosis is being "sought" for children in this subgroup in higher SES families.

Based on our review, we suggest the following 4 explanations for the late diagnosis of ASD:

1. The presence of other developmental concerns or diagnoses may have masked or overshadowed an ASD diagnosis.[4,5,16] Indeed, in our cohort, we found that many children were diagnosed initially with developmental language disorders and motor difficulties, and almost half of the sample was diagnosed with ADHD features and behavior problems.

2. The child's presentation changed or evolved, and ASD criteria were truly met at a later age after not having been present at an earlier age. This may reflect an evolving diagnostic picture in some children with later diagnoses of ASD and possibly even a unique phenotype of ASD that arises because of developmental processes. This possibility applies especially to children in Positive ASD Features Group, who commonly had inappropriate social and pragmatic deficits, similar to the features noted in children diagnosed late in a previous study.[8] It is feasible that as children age, social demands increase, and social and pragmatic deficits become more obvious and lead to an ASD diagnosis, as is being proposed in DSM-5 criteria for ASD.[17]

3. Features of ASD could have been overlooked during comprehensive evaluations; and therefore, the diagnosis may have been missed at early ages. That is, ASD was underdiagnosed at earlier evaluations. This explanation could apply to children in Positive ASD Features Group (who had autistic features documented through the age of 6), especially for those with a diagnostic impression of communication problems (12% of the cohort), where it is possible that features were not assigned sufficient importance. Multiple evaluations by a variety of professionals and team meetings should have decreased the possibility of a missed ASD diagnosis but obviously could not eliminate it completely.

4. Late ASD diagnoses may have been assigned to "borderline" or otherwise developmentally complex children, despite previous documentation refuting an ASD diagnosis. Put another way, ASD is being overdiagnosed at later evaluations. This explanation is consistent with our findings, because for the majority of the cohort, no initial ASD-suggested features were noted through the age of 6 (No Early ASD Features Group). One reason for the overdiagnosis could be the increased benefits

for children with ASD: in 2008, the Israeli government changed the "benefit basket" for children with ASD, offering more treatments up to the age of 18 years, in addition to the treatments provided by the special education system,[18] potentially creating an incentive for an ASD diagnosis. Our findings are consistent with this reason, as between 2004 and 2007, 17% of the study cohort received an ASD diagnosis, whereas 83% were diagnosed in the next 4 years after the implementation of the new benefits (2008–2011). The combination of increased benefits for children with ASD, in addition to increased ASD awareness, may cause providers to feel pressure from families to assign ASD diagnoses in borderline cases. A second possible reason for overdiagnosis is the lack of reliance on formal assessments, despite guidelines that recommend otherwise.[19] ASD diagnoses are often assigned outside of specialized diagnostic settings, without the use of ASD-specific assessments[20] or the DSM-4.[11] It should be noted that 61.9% of the total group had additional confirmation of ASD diagnosis through review of completed DSM-4 criteria to permit access to ASD treatment services, indicating an additional level of review of ASD diagnosis, and less suggestive of overdiagnosis.

This report has several strengths, including a highly detailed chart review of a large cohort of children seen in a single health care system. This longitudinal review also allows for a comprehensive retrospective analysis of a specific cohort. Limited access to information about the details of how ASD diagnoses were assigned at later ages is a weakness and lack of information on ASD diagnosis subtypes. In some cases, use of ASD-specific diagnostic tools may have been indicated at the time of initial evaluation (under age 6); however, ASD-specific diagnostic tools were not used routinely in MCDC throughout the course of this study. The intent of this study was not to compare a later diagnosis group with an early diagnosis group, but rather to describe this unique, but not rare, group of children receiving an ASD diagnosis at a later age after a previous ASD-negative assessment. The scenario we describe is a familiar one to many clinicians and warrants further investigation.

With prevalence of ASD growing at alarming rates, increasing burden on service systems for individuals with ASD and the need for well-defined and characterized populations on whom to conduct important research, the issues of misdiagnosis, overdiagnosis, and missed diagnosis of ASD will need to be further investigated and understood.

Gaining an improved understanding of appropriate diagnostic methods used in making a later diagnosis of ASD and an improved understanding of the developmental trajectory of children with a wide range of developmental concerns are both important

opportunities for additional studies. Longitudinal follow-up of children with early developmental diagnoses will inform the question of developmental trajectory and possible shift into a diagnosis of ASD. Until a biomarker for ASD is identified, ASD diagnosis will be based on clinical impressions and tools, and there is still significant variability across clinicians in making these diagnoses. Understanding and mitigating this variability is critical to improving our understanding of ASD.

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