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Heterogeneity in Autism Spectrum Disorder Case-Finding Algorithms in United States Health Administrative Database Analyses

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Abstract

Strengthening systems of care to meet the needs of individuals with autism spectrum disorder (ASD) is of growing importance. Administrative data provide advantages for research and planning purposes, including large sample sizes and the ability to identify enrollment in insurance coverage and service utilization of individuals with ASD. Researchers have employed varying strategies to identify individuals with ASD in administrative data. Differences in these strategies can limit the comparability of results across studies. This review describes implications of the varying strategies that have been employed to identify individuals with ASD in US claims databases, with consideration of the strengths and limitations of each approach.

Keywords

Health services research; Claims data; Autism spectrum disorder; Case-finding algorithms

Autism spectrum disorder (ASD) is a developmental disability defined by deficits in social communication and social interaction and the presence of restricted, repetitive patterns of behavior, interests, or activities. These symptoms can persist with varying degrees throughout life. ASD is also often referred to as pervasive developmental disorder (PDD). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) combines what in the fourth edition, DSM-IV, were classified as four independent diagnoses —autistic disorder, Asperger syndrome, pervasive developmental disorder-not otherwise

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specified and childhood disintegrative disorder—into a single diagnostic category, ASD (American Psychiatric Association, 1994, 2013).

Administrative databases with person-level information on diagnoses, services received, and provider charges or payments have increasingly been used for health services research due to their ready availability, low cost, and the opportunity to assess real-world treatment patterns for large numbers of individuals with chronic or acute disorders (Riley, 2009; Vaughan Sarrazin & Rosenthal, 2012). The two major types of US administrative healthcare data are hospital discharge databases, which report hospital-based encounters that typically cannot be linked to unique patients, and insurance claims databases that track services received by individuals across inpatient and outpatient settings, including prescription medications (Grosse et al., 2020; Riley, 2009). Hospital discharge databases have the advantage of representing the entire population whereas claims databases are restricted to individuals covered by health plans that contribute data. Our focus in this review is analyses of US health insurance databases, which contain billing claims but not certified medical diagnoses.

Researchers who analyze US health administrative data for conditions, such as ASD, generally use diagnosis codes developed for billing purposes as proxies for medical diagnoses. However, methodological nuances and challenges in the application of diagnosis codes in administrative data can hinder the accurate ascertainment of individuals with the conditions of interest (Hinds et al., 2016; McPheeters et al., 2013a; Vaughan Sarrazin & Rosenthal, 2012). The sensitivity and specificity of billing codes are variable, depending on both the condition of interest (Quan et al., 2008; Rector et al., 2004) and the setting of care. Inpatient coding is typically highly specific, since hospitals have trained coders and standardized quality assurance processes for billing claims, whereas diagnosis codes in outpatient claims are more likely to be false-positives due to coding errors (Andrade et al., 2013; McPheeters et al., 2013b; Metcalfe et al., 2014; Mullooly et al., 2008; Ronald et al., 2017; Sickbert-Bennett et al., 2011; Worth & Mytinger, 1996). In the US context, such differences can also result from inpatient diagnosis codes receiving closer scrutiny from payers because they affect reimbursements, whereas reimbursements for outpatient claims are influenced by procedure codes and not by diagnosis codes (Lanes et al., 2015). In addition, false-positive diagnosis codes can represent “rule-out” billing codes for evaluation visits, laboratory tests or imaging procedures.

To improve specificity, researchers who analyze claims data often require more than one outpatient claim on different days. For example, the positive predictive value (PPV) for a single outpatient claim with a code for muscular dystrophy in one study was 22.6%, but an algorithm with one inpatient claim or two or more outpatient claims at least 30 days apart with specified diagnosis codes had a PPV of 59.3% (Smith et al., 2017). The Center for Medicare and Medicaid Services (CMS) Chronic Conditions Data Warehouse lists case-finding algorithms for 66 chronic or potentially disabling conditions (including ASD since 2013), most of which require the presence of a diagnosis code on either one inpatient claim or two or more non-inpatient or non-drug claims within a 2-year reference period (Centers for Medicare and Medicaid Services, 2019). For sickle cell disease, most researchers require the presence of diagnosis codes in either one inpatient claim or two or

more outpatient claims on separate days or three or more claims in any setting on separate days (Grosse et al., 2020).

Algorithms can also miss individuals (false-negative diagnoses) for at least one of the following reasons: (1) the individual had no encounters during the study period or the encounter was billed to a separate insurance type; (2) the individual received a diagnosis, but it was not included in medical charts; (3) the diagnosis was included in medical charts but not listed on a claim during the study period; (4) the diagnosis was listed on a claim, but it was not recorded in the billing database; or (5) the individual received a diagnosis, but it was incorrectly recorded in the billing database.

Claims databases may include records of encounters for individuals enrolled in both fee-for-service (FFS) and managed care plans. Technically, FFS records represent claims for reimbursement, whereas managed care plans include records for encounters with diagnosis codes and imputed payments. However, the completeness of records from managed care plans varies, since payers may insert the imputed capitated rate or average service experience of all enrollees instead of the unique service experience of individuals. In addition, some health plans “carve out” behavioral health services that are paid under separate contracts (Frank & Garfield, 2007); consequently claims data for such plans may miss important information on services for children with ASD.

Although there are inherent limitations in the use of administrative claims data, the proportion of individuals correctly classified using case-finding algorithms in claims data can vary based on a number of decisions made by the research team, such as the choice of diagnosis codes included, the number of claims required (e.g., at least one vs. two or more), dates on which claims occur, the age range, enrollment criteria, health plan type, and coding quality.

In this paper, we review the approaches that have been used with US administrative claims and encounters data to classify children as having ASD. Specifically, we review studies that used *International Classification of Diseases, Ninth Revision, Clinical Modifications* (ICD-9-CM) diagnosis codes. The Center for Medicare and Medicaid Services (CMS) required that US healthcare providers use ICD-9-CM codes through September 30, 2015 or *International Classification of Diseases, Tenth Revision, Clinical Modifications* (ICD-10-CM) codes beginning on October 1, 2015. The 299.x ICD-9-CM diagnosis codes for ASD and the 330.8 code for Rett syndrome and the corresponding F84.x ICD-10-CM codes are shown in Table 1. Rett syndrome is not included in the DSM-5 case definition for ASD but can be used as a genetic specifier for a case of ASD that also meets diagnostic criteria for Rett syndrome (American Psychiatric Association, 2013; Reichow et al., 2015).

In the Discussion section, we briefly summarize results from six published validation studies that have used record linkages of administrative healthcare data with ASD diagnosis codes to clinical data used to identify confirmed or probable ASD cases (Bickford et al., 2020; Burke et al., 2014; Coleman et al., 2015; Coo et al., 2018; Dodds et al., 2009; Rotem et al., 2020). The ultimate purpose of this review is to facilitate researchers’ ability to assess the potential implications of the choice of claims-based algorithms for ASD.

Case-Finding Algorithms for Autism Spectrum Disorder

We conducted a scoping review of US studies indexed in PubMed from January 2006 through February 2020 that examined claims with ICD-9-CM diagnosis codes in healthcare administrative databases, including claims with both outpatient and inpatient encounters in their analyses, in order to identify individuals with suspected or presumed ASD or PDD. A scoping review provides for the structured capturing of relevant literature but does not include an assessment of the quality of each research article. Searches on terms included in either article titles or abstracts are listed in supplemental Table S1, which yielded a total of 1,503 publications. Two authors reviewed all article titles and abstracts and reached consensus about articles that met the study criteria.

We excluded studies that did not use US data or may have used ICD-9-CM codes but also relied on other types of data for case ascertainment, such as survey or surveillance data. Likewise, studies that combined administrative healthcare data with other types of data, such as medical records or school records, were not included in our primary review. Electronic health records were not included because they include diagnoses obtained from both encounters and patient problem lists. We also excluded studies that used claims data to identify possible cases for subsequent confirmation or subsets of cases of individuals with ASD based on use of specific types of services (e.g., behavioral health services) or specific procedure codes or co-occurring diagnoses, such as anxiety and depression. We excluded two studies that identified individuals with ASD as a subset of individuals with a broader group of diagnoses of intellectual or developmental disabilities (McDermott et al., 2018; Phillips et al., 2019). Finally, we excluded studies that attempted to identify incident rather than prevalent cases of ASD.

The inclusion and exclusion criteria and definition were established to minimize bias from studies that selected only a subset of individuals with ASD. Studies that combined administrative healthcare data with other sources, such as school records, were excluded since ASD diagnoses in education records may have greater predictive accuracy than those in healthcare administrative data (Coo et al., 2018). From the list of studies identified, the title, authors, PubMed ID, and year of publication were extracted and classified as either meeting the inclusion criteria or categorized by which exclusion criteria each article met. A total of 63 studies that met our inclusion and exclusion criteria are summarized in Table 2.

ICD-9-CM Codes

The 63 studies used the presence of either 3-digit ICD-9-CM diagnosis code 299 or a subset of 4- or 5-digit ASD coded billing claims to identify potential ASD/PDD cases. The four 4-digit ICD-9-CM codes used for ASD, along with the DSM-IV and ICD-9-CM definitions, are 299.0 for autistic disorder (DSM-IV) or infantile autism (ICD-9-CM), 299.1 for childhood disintegrative disorder (DSM-IV) or disintegrative psychosis (ICD-9-CM), 299.8 for Asperger's disorder and other specified PDD (DSM-IV) or other specified early childhood psychoses (ICD-9-CM), and 299.9 for unspecified PDD (ICD-9-CM) (American Psychological Association, 2002). Each 4-digit ICD-9 code has two 5-digit codes, ending in either 0 for "current or active state" or 1 for "residual state," a distinction in DSM-III that was dropped from DSM-IV (Volkmar, 2013). One of the 63 studies used both the

ICD-9-CM 299.x codes and the corresponding ICD-10-CM codes of F84.x (Rubenstein & Bishop, 2019). Given that the level of specificity of the 5-digit ICD-9-CM codes was no longer considered clinically meaningful after the 1994 publication of DSM-IV, from hereon we refer to 4-digit ICD-9-CM codes unless otherwise specified.

The claims-based ASD algorithms used in these 63 studies differ based on the selection of diagnosis codes. Almost half of the included studies (n = 29) used all 299.x ICD-9-CM codes to ascertain presumed ASD/PDD cases (Barry et al., 2017, 2019; Candon et al., 2018, 2019; Chi et al., 2016; Cidav et al., 2013, 2014; House et al., 2016; Jariwala-Parikh et al., 2019; Kalb et al., 2019; Kang-Yi et al., 2016; Kennedy-Hendricks et al., 2018; Khanna et al., 2013; Leslie & Martin, 2007; Mandell et al., 2006, 2010, 2016; Matone et al., 2012; Nathenson & Zablotsky, 2017; Oswald & Sonenklar, 2007; Peng et al., 2009; Saloner & Barry, 2019; Shea et al., 2014, 2018; Stuart et al., 2017; Vohra et al., 2016, 2017; Wang et al., 2019; Williams et al., 2012). One of the 29 studies additionally listed a diagnosis code of 330.8 for Rett syndrome as an inclusion criterion for ASD (Peng et al., 2009).

The remaining 34 studies excluded one or more of the 299.x codes. Most of those studies (n = 22) excluded the 299.1 code for childhood disintegrative disorder from the codes used to identify ASD cases but used all other codes, 299.0, 299.8, and 299.9 (Bishop-Fitzpatrick & Rubenstein, 2019; Burke et al., 2014; Cidav et al., 2018; Cohrs & Leslie, 2017; Coleman et al., 2015; Cummings et al., 2016; Heifert et al., 2016; Hisle-Gorman et al., 2018; Houghton et al., 2017; Jain et al., 2014, 2015; Lee et al., 2018; Mandell et al., 2008, 2012; McDermott et al., 2008; Rubenstein & Bishop, 2019; Rubin et al., 2009; Shedlock et al., 2016; Sigmon et al., 2019; Spencer et al., 2013; Vargason et al., 2019; Wang & Leslie, 2010). Eight of those 22 studies also excluded from their ASD case definition any child who had claims with codes of 299.1 or 330.8 associated with either childhood disintegrative disorder or Rett syndrome even if they also had claims with codes of 299.0, 299.8, or 299.9 (Burke et al., 2014; Hisle-Gorman et al., 2018; Jain et al., 2014; Lee et al., 2018; Shedlock et al., 2016; Sigmon et al., 2019; Spencer et al., 2013; Vargason et al., 2019).

Twelve studies used other combinations of ICD-9-CM codes. Six used just the 299.0 and 299.8 codes, excluding both 299.1 and 299.9 codes (Croen et al., 2006; Liu et al., 2017, 2019; Peacock et al., 2012; Shimabukuro et al., 2008; Wang et al., 2013). Five studies used the combination of 299.0, 299.1, and 299.8 codes, excluding just 299.9 (Flanders et al., 2006, 2007; Mandell et al., 2010; Schubart et al., 2014; Stein et al., 2012). One of those studies additionally listed a diagnosis code of 330.8 for Rett syndrome as an inclusion criterion for ASD (Flanders et al., 2006). Finally, one study was restricted to claims with a 299.0 code for autistic disorder or a 299 3-digit code without a modifier (Daniels & Mandell, 2013).

Numbers of Claims

Algorithms also differ in the minimum number of claims on separate dates and whether they treat claims differentially based on care setting (inpatient vs. outpatient), or diagnosis field (principal vs. other). The primary distinction is between studies that required just one ASD claim and studies that required two or more ASD claims on separate dates to establish presumptive diagnosis of ASD.

We found 19 studies that considered a claim with the presence of a single ASD diagnosis code in any setting to be sufficient to identify someone with ASD. Of the 19 studies that required just one code, 17 did not specify diagnosis field (Chi et al., 2016; Croen et al., 2006; Flanders et al., 2006, 2007; House et al., 2016; Jariwala-Parikh et al., 2019; Khanna et al., 2013; Leslie & Martin, 2007; Mandell et al., 2008, 2016; Matone et al., 2012; McDermott et al., 2008; Oswald & Sonenklar, 2007; Rubin et al., 2009; Shimabukuro et al., 2008; Wang & Leslie, 2010; Williams et al., 2012). Two studies required a claim with an ASD code as the first-listed diagnosis code (Stein et al., 2012; Stuart et al., 2017).

Of the 44 other studies listed in Table 2, 31 required two claims with ASD codes on separate dates in any setting, either in any diagnosis field (Barry et al., 2017; Bishop-Fitzpatrick & Rubenstein, 2019; Burke et al., 2014; Candon et al., 2018, 2019; Cohrs & Leslie, 2017; Coleman et al., 2015; Cummings et al., 2016; Heifert et al., 2016; Hisle-Gorman et al., 2018; Houghton et al., 2017; Jain et al., 2014, 2015; Kalb et al., 2019; Kennedy-Hendricks et al., 2018; Lee et al., 2018; Liu et al., 2017, 2019; Mandell et al., 2006, 2019; Peng et al., 2009; Rubenstein & Bishop, 2019; Shea et al., 2018; Shedlock et al., 2016; Sigmon et al., 2019; Spencer et al., 2013; Vargason et al., 2019; Wang et al., 2019) or in a first-listed diagnosis field (Kang-Yi et al., 2016; Mandell et al., 2012; Saloner & Barry, 2019). The remaining 13 studies treated one ASD claim in an inpatient setting as equivalent in presumed validity to two outpatient ASD claims on separate dates, either in any diagnosis field (n = 9) (Barry et al., 2019; Cidav et al., 2018; Mandell et al., 2010; Peacock et al., 2012; Schubart et al., 2014; Shea et al., 2014; Vohra et al., 2016, 2017; Wang et al., 2013) or in a principal diagnosis field (n = 4) (Cidav et al., 2013, 2014; Daniels & Mandell, 2013; Nathenson & Zablotsky, 2017). One of the 13 studies required outpatient claims for ASD to be separated by at least 30 days (Peacock et al., 2012).

Reference Period

Another dimension that might affect the predictive power of an algorithm for ASD case ascertainment as well as the characteristics of identified cases is the length of time over which claims are assessed, which varied greatly. The reference period over which administrative data were searched to ascertain ASD cases was not necessarily the total number of years of data analyzed. In addition, studies did not necessarily require continuous enrollment throughout the reference period. The length of the reference period was 6 months in one study (Mandell et al., 2012) and 1 year in 21 other studies (Cidav et al., 2013, 2014; Cohrs & Leslie, 2017; Croen et al., 2006; Flanders et al., 2007; Houghton et al., 2017; Kang-Yi et al., 2016; Khanna et al., 2013; Leslie & Martin, 2007; Mandell et al., 2006, 2008, 2010; McDermott et al., 2008; Oswald & Sonenklar, 2007; Rubin et al., 2009; Schubart et al., 2014; Shea et al., 2014, 2018; Stein et al., 2012; Wang & Leslie, 2010; Wang et al., 2013). Many of those studies included multiple years of claims data, with repeated cross-sections of annual data used to identify cases in specific years.

The reference period for case ascertainment was 2–3 years in four studies (Cummings et al., 2016; Flanders et al., 2006; Jariwala-Parikh et al., 2019; Peacock et al., 2012), 4–5 years in 13 studies (Barry et al., 2017, 2019; Bishop-Fitzpatrick & Rubenstein, 2019; Candon et al., 2018, 2019; Daniels & Mandell, 2013; House et al., 2016; Kalb et al., 2019; Kennedy-

Hendricks et al., 2018; Mandell et al., 2016, 2019; Saloner & Barry, 2019; Williams et al., 2012) and 6–7 years in five studies (Cidav et al., 2018; Matone et al., 2012; Peng et al., 2009; Stuart et al., 2017; Wang et al., 2019). Finally, 19 studies searched 9 or more years of data to identify ASD cases (Burke et al., 2014; Chi et al., 2016; Coleman et al., 2015; Heifert et al., 2016; Hisle-Gorman et al., 2018; Jain et al., 2014, 2015; Lee et al., 2018; Liu et al., 2017, 2019; Nathenson & Zablotsky, 2017; Rubenstein & Bishop, 2019; Shedlock et al., 2016; Shimabukuro et al., 2008; Sigmon et al., 2019; Spencer et al., 2013; Vargason et al., 2019; Vohra et al., 2016, 2017). One of the latter studies reported a primary analysis that searched 11 years of claims data (1993–2003) for ASD codes and a secondary analysis restricted to 1 year of data, 2003, to identify current-year ASD cases (Shimabukuro et al., 2008).

Discussion

Of the 63 studies that met our inclusion criteria (Table 2), 29 included all four 4-digit 299.x ICD-9-CM codes for ASD. Of 34 studies that used subsets of those codes, most (n = 27) excluded the 299.1 code for childhood disintegrative disorder. The DSM-5 in 2013 explicitly classified ASD as encompassing childhood disintegrative disorder. However, the DSM-5 excluded Rett syndrome from ASD, although if another qualifying diagnosis of ASD was made a child with a diagnosis of Rett syndrome (ICD-9-CM code 330.8; ICD-10 code F84.2) should not be excluded (Reichow et al., 2015). The two studies that listed 330.8 as an inclusion criterion were published in 2006 and 2009. All 10 studies that excluded individuals with a 330.8 code, regardless of the presence of ASD diagnosis codes, were published in 2013 or later, even though that exclusion is inconsistent with the DSM-5 protocol.

The minimum number of claims with ASD diagnosis codes, either overall or by setting type (inpatient or outpatient), also varied. Of the three main approaches, 19 studies required a minimum of one ASD claim in any setting, 31 required two or more ASD claims in any setting, and 13 required the presence of an ASD code in either one inpatient claim or two or more outpatient claims. Until recently, the presence of one claim for a clinical encounter with an ASD diagnosis code was commonly considered sufficient to establish a presumptive diagnosis of ASD. Among 23 studies published prior to 2014, 15 required a minimum of one claim with an ASD diagnosis code (Croen et al., 2006; Flanders et al., 2006, 2007; Khanna et al., 2013; Leslie & Martin, 2007; Mandell et al., 2008; Matone et al., 2012; McDermott et al., 2008; Oswald & Sonenklar, 2007; Peng et al., 2009; Rubin et al., 2009; Shimabukuro et al., 2008; Stein et al., 2012; Wang & Leslie, 2010; Williams et al., 2012). In contrast, among 40 studies published since 2014, just five had the same minimal requirement (Chi et al., 2016; House et al., 2016; Jariwala-Parikh et al., 2019; Mandell et al., 2016; Stuart et al., 2017).

The increasingly common pattern of case-finding algorithms for ASD requiring multiple outpatient claims on separate days with ASD codes may have been influenced by a widely cited 2014 publication of a validation study (Burke et al., 2014). Burke et al. found a high PPV (87%) relative to an expert clinical assessment of confirmed or probable ASD case status for an algorithm requiring an ASD code in two or more encounters in any setting in 8 years of records from a large health plan. Three subsequent validation studies from the

United States and Canada similarly reported PPVs of 87–89% for algorithms requiring ≥ 2 claims or encounters with ASD diagnosis codes on separate dates, using 14–15 years of data (Bickford et al., 2020; Coleman et al., 2015; Coo et al., 2018).

Published analyses that cite these validation studies may not necessarily adhere to the recommendations of those studies. For example, many studies that cited the predictive value of the study by Burke et al. did not use the same diagnosis codes to identify presumed ASD cases that were used in that study. A recently published analysis of private health insurance data that required ≥ 3 ASD codes on separate encounters during a 6-year period cited Coleman et al. (2015) as their justification (Feroe et al., 2021), even though that validation study did not assess such an algorithm. The requirement of ≥ 3 diagnosis codes on separate encounters over 5 years of data has, however, been endorsed for use in identifying cases of sickle cell disease (Grosse et al., 2020).

On the other hand, requiring the presence of multiple claims with ASD diagnosis codes almost inevitably results in the exclusion of individuals with ASD. All five North American validation studies found that most children with ≥ 1 ASD-related claim were confirmed or probable ASD cases (Bickford et al., 2020; Burke et al., 2014; Coleman et al., 2015; Coo et al., 2018; Dodds et al., 2009). Indeed, one US study found that the majority of children with just 1 ASD claim had confirmed ASD diagnoses, although that study oversampled records from specialists, whose coding was more accurate (Burke et al., 2014). A recent study from Israel reported that among children with ≥ 1 ASD-related insurance claims, most were confirmed to have ASD through participation in a publicly funded program, and that chart reviews for the remaining children found that almost half met diagnostic criteria for ASD (Rotem et al., 2020).

A reasonable argument can be made for using the less restrictive case definition of ≥ 1 ASD-related claim or healthcare encounter, depending on the study purpose if maximizing sensitivity is considered more important than maximizing specificity. The first published validation study of ASD diagnosis codes suggested that maximizing sensitivity was most important and recommended that Canadian researchers use the presence of even 1 ASD diagnosis code in any administrative healthcare database (inpatient, outpatient physician, or outpatient mental health) be used to assign ASD case status (Dodds et al., 2009).

The choice of reference period over which claims are assessed for ASD codes also varied widely, from 1 year or less to more than 10 years. Most studies (n = 37) used 4 or more years of claims data as a reference period to ascertain ASD case status. Only five of those 37 studies were published prior to 2014, compared with 18 of 26 studies that used shorter reference periods. Some recent publications have used relatively short reference periods (e.g., 1 year) whether due to restricted data availability, logistical factors, or a desire to conduct trend analyses using 1 calendar year as the unit of observation. As previously noted, studies did not generally require continuous enrollment throughout multi-year reference periods. Requiring continuous enrollment for several years would greatly reduce the sample size, particularly for children in younger age groups, and could introduce selection bias based on factors that influence long-term participation in healthcare databases.

Of the 13 included studies that required either one inpatient claim or two or more outpatient claims with ASD codes, none cited the CMS Chronic Conditions Data Warehouse as justification for the choice of that algorithm. Moreover, none of those studies chose to use the 2-year reference period recommended in that source (Centers for Medicare and Medicaid Services, 2019). Similarly, a National Academies report in 2015 that analyzed Medicaid Analytic eXtract data for mental disorders in children required either one inpatient claim or two or more outpatient claims with ASD codes within a single calendar year of data (National Academies of Sciences, 2015).

The completeness of coding may differ between FFS and managed care plans. In CMS Medicaid Analytic eXtract data, the completeness of managed care encounters is reported to have increased over time with large gaps across states (Byrd & Dodd, 2012, 2015). Many studies have used only FFS Medicaid claims data (Bishop-Fitzpatrick & Rubenstein, 2019; Khanna et al., 2013; Leslie & Martin, 2007; Mandell et al., 2006; Schubart et al., 2014; Vohra et al., 2016, 2017; Wang et al., 2013), including individuals enrolled in managed care plans with mental health services paid through FFS (Cidav et al., 2013, 2014; Shea et al., 2018).

It is unclear how the accuracy of ASD case-finding algorithms might differ by age group. Since validation studies have been focused on younger children, little information is available on the accuracy of claims data for identifying adolescents and adults with ASD. Differences across age groups in recorded ASD prevalence or healthcare use in administrative data might reflect both true differences and differences in sensitivity and specificity of the case-finding algorithms. A growing number of health services research studies using administrative data have focused on transition-age youth with ASD (Kalb et al., 2019; Liu et al., 2017; Nathenson & Zablotsky, 2017; Shea et al., 2018).

Analyses of claims data from other countries also vary in ASD case finding algorithms, and this variability in coding practices could affect the comparability of published estimates. For example, studies using Taiwan's National Health Insurance Research Database (NHIRD) have also applied different ASD case-finding algorithms using ICD-9 299 codes for ASD, e.g., ≥ 1 claim in any setting (Chan et al., 2021), either ≥ 1 inpatient or ≥ 2 outpatient ASD claims (Yu et al., 2021), or either ≥ 1 (Tsao et al., 2017), ≥ 2 (Lee et al., 2016), or ≥ 3 outpatient physician visits (Dai et al., 2019; Huang et al., 2021; Hung et al., 2021). Some analyses of Taiwan NHIRD data have required the presence of ASD ICD-9 diagnosis codes for encounters with a board-certified psychiatrist (Dai et al., 2019; Lee et al., 2016; Tsao et al., 2017) or a pediatric psychiatrist, psychologist, or neurologist (Hung et al., 2021). The National Insurance Institute of Israel maintains a national claims database that, since 2007, has confirmed ASD claims based on a diagnostic evaluation by a pediatric psychiatrist, pediatric neurologist, a pediatrician with at least 3 years of experience in a certified child development center in addition to an assessment by a developmental or clinical psychologist (Pinto & Raz, 2021; Raz et al., 2015).

Conclusions

The lack of standardization in ASD case algorithms for identifying cases in administrative claims data could pose a challenge to the synthesis of evidence from epidemiologic and health services research studies. Such limitations are not unique to administrative data; ASD diagnoses reported by respondents in the Medical Expenditure Panel Survey were recorded using ICD-9-CM codes (Cidav et al., 2012; Kalb et al., 2019; Lavelle et al., 2014; Liptak et al., 2006; Zuvekas et al., 2021). Additionally, state governments and other agencies often use administrative data to track and report service use and needs. An evidence-based standardized approach could facilitate comparisons in healthcare use and service needs across states and other entities and over time. However, standardization might require additional evidence from validation studies conducted using broader age ranges and representativeness of validation cohorts.

It could be helpful if researchers were to report results on how outcome measures, such as healthcare use or expenditures, vary depending on the data source, case definition, and the number of years of data used to ascertain ASD cases (Zuvekas et al., 2021). Children who meet a case-finding algorithm requiring multiple claims within 1 calendar year typically use more healthcare resources on average than other children who only meet the same case-finding algorithm using multiple years of data (Amendah et al., 2010). An analysis of claims data has reported that 0.56% of children aged 3–7 years in 2011 had ≥ 2 claims with ASD diagnosis codes during 2011 and 1.33% of the same group of children had ≥ 2 such claims at any point during 2011–2015, with mean spending during 2011 (in 2017 dollars) of $13,198 and $8,685, respectively (Grosse et al., 2021).

The optimal case-finding algorithm for ASD may vary with the purpose of a study. For studies of risk factors for ASD, a high PPV is likely to be the most important criterion (Burke et al., 2014). Similarly, since inclusion of false-positive cases in analyses of healthcare utilization and expenditures can result in underestimation of costs for children with ASD, an algorithm with relatively few false-positives may be preferred. Studies that set a low bar of just one ASD diagnosis code are likely to include substantial numbers of individuals who do not meet diagnostic criteria for ASD, and such misclassification error is likely to bias estimates of associations with risk factors or incremental use of healthcare services associated with ASD to the null.

A longer time window (multiple years of data) used to identify ASD cases may improve sensitivity, including individuals who have relatively few formal healthcare encounters or have disruptions in healthcare coverage. That has important implications for analyses of economic impact since use of a single calendar year of data to identify case status, although useful for analyses of trends, can substantially overstate estimates of mean healthcare use and expenditures (Grosse et al., 2021). On the other hand, analyses of claims data to estimate administrative prevalence of ASD as a complement to population-based surveillance methods might consider adopting a relatively broad case-finding algorithm, explicitly trading off more false positives to reduce the number of false negatives. Epidemiologic modeling of data from validation studies could help in assessing the potential algorithms from that perspective. Validation studies have reported that the majority of

children with a single ASD claim during a multi-year period are either definite or probable ASD cases (Burke et al., 2014; Coo et al., 2018; Dodds et al., 2009; Rotem et al., 2020).

In summary, although much progress in identifying appropriate ASD case-finding algorithms for health services research has been made in recent years, additional validation studies may help researchers choose among case-finding algorithms.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

ASD	Autism spectrum disorder
CMS	Center for Medicare and Medicaid Services
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, fourth edition
FFS	Fee-for-service
ICD-9-CM	International Classification of Diseases, Ninth Revision, Clinical Modification
ICD-10-CM	International Classification of Diseases, Tenth Revision, Clinical Modification
PDD	Pervasive developmental disorder
PPV	Positive predictive value

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Table 1

ICD-9-CM and ICD-10-CM diagnosis codes for autism spectrum disorder diagnosis types

Condition	ICD-9-CM codes[a]	ICD-10-CM codes[a]
Autistic disorder	299.00, 299.01	F84.1
Childhood disintegrative disorder	299.10, 299.11	F84.3
Rett syndrome	330.8	F84.2
Asperger's syndrome	299.80, 299.81	F84.5
Other pervasive developmental disorders	299.80, 299.81	F84.8
Pervasive developmental disorder, unspecified	299.90, 299.91	F84.9

ICD-9-CM International Classification of Diseases, Ninth Revision, Clinical Modifications, *ICD-10-CM* International Classification of Diseases, Tenth Revision, Clinical Modifications

ICD-9-CM recommended for use by US healthcare providers through September 30, 2015

ICD-10-CM recommended for use by US healthcare providers starting October 1, 2015

[a]These codes are consistent with the definition of autism spectrum disorder in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*

Table 2

Summary of US studies indexed in PubMed using the presence of ICD-9-CM diagnosis codes for autism spectrum disorder to identify presumed cases, January 2006–February 2020

Study	ICD-9/10-CM codes used to include or exclude ASD cases (exclusion criteria in parentheses)	Type of algorithm[a]	Years of data used for case ascertainment	Continuous enrollment requirement (months)	Age range (years)	Type of health plans or data source
Barry et al. (2017)	299.xx	B1	2008–2012, all years used	None	0 to 21	Private
Barry et al. (2019)	299.xx	C1	2008–2012, all years used	None	0 to 21	Private
Bishop-Fitzpatrick and Rubenstein (2019)	299.0x, 299.8x, and 299.9x	B1	2012–2015, all years used	None	40 and older	Fee-for-service Medicaid
Burke et al. (2014)	299.0x, 299.8x, and 299.9x (excluded cases with 299.1x or 300.8)	B1	2001–2009, all years used	12 (6 months before and after claim	2 to 20	Private
Candon et al. (2018)	299.xx	B1	2008–2012, all years used	None	0 to 21	Private
Candon et al. (2019)	299.xx	B1	2008–2012, all years used	None	< 20	Private
Chi et al. (2016)	299.xx	A1	2003–2011, all years used	11–12	3 to 17	Medicaid
Cidav et al. (2013)	299.xx	C2	2005	12	3 to 20	Fee-for-service Medicaid
Cidav et al. (2014)	299.xx	C2	2005		0 to 20	Fee-for-service Medicaid
Cidav et al. (2018)	299.00, 299.8, 299.9	C1	2001–2007, all years used	6 months	2 to 17	Medicaid
Cohrs and Leslie (2017)	299.0x, 299.8x, and 299.9x	B1	2011	None	1 to 17	Private
Coleman et al. (2015)	299.0x, 299.8x, and 299.9x	B1	1995–2010, all years used	None	Under 18 in 2010	Mental Health Research Network
Croen et al. (2006)	299.0x and 299.8x	A1	2003–2004, 12 months	12	2 to 18	HMO
Cummings et al. (2016)	299.0x, 299.8x, and 299.9x	B1	2009–2010, all years used	10	3 to 17	Mental Health Research Network
Daniels and Mandell (2013)	299.0x or 299	C2	2001–2005, all years used	10 months each year from birth to ASD diagnosis	Born in 2001	Medicaid
Flanders et al. (2006)	299.0x, 299.1x, 299.9x and 330.8	A1	January 2001–June 2003, all years used	90 days before & 180 days after diagnosis	3 to 17	Private
Flanders et al. (2007)	299.0x, 299.1x, and 299.8x	A1	1996–2002, annual	90 days before & 180 days after diagnosis	3 to 17	Medicaid
Heifert et al. (2016)	299.0x, 299.8x, and 299.9x	B1	October 2000–September 2013, all years used	Enrollment required 6 months pre- and post-diagnosis	2 to 18	Military Health System

Study	ICD-9/10-CM codes used to include or exclude ASD cases (exclusion criteria in parentheses)	Type of algorithm[a]	Years of data used for case ascertainment	Continuous enrollment requirement (months)	Age range (years)	Type of health plans or data source
Hisle-Gorman et al. (2018)	299.0x, 299.8x, and 299.9x, (excluded cases with 299.1x or 330.8)	B1	October 2000–September 2013, all years used	None	2 to 18	Military Health System
House et al. (2016)	299.xx	A1	2007–2010, all years used	None	0 to 17	Private
Houghton et al. (2017)	299.0x, 299.8x, and 299.9x	B1	2014	None	3 to ≥ 50	Private and Medicaid
Jain et al. (2014)	299.0x, 299.8x, and 299.9x (excluded cases with 299.1x or 300.8x)	B1	2001–2009, all years used	6	0 to 20	Private
Jain et al. (2015)	299.0x, 299.8x, and 299.9x	B1	2001–2012, all years used	60	Cumulative to ages 5–11	Private
Jariwala-Parikh et al. (2019)	299.xx	A1	2006–2008, all years used	Continuous	18 to 64	Medicaid
Kalb et al. (2019)	299.xx	B1	2010–2013, all years used	12	12 to 17	Private
Kang-Yi et al. (2016)	299.xx	B2	October 2008–September 2009	None	5 to 17	Medicaid
Kennedy-Hendricks et al. (2018)	299.xx	B1	2008–2012, all years used	None	10 to 21	Private
Khanna et al. (2013)	299.xx	A1	2007	12	Under 65	Fee-for-service Medicaid
Lee et al. (2018)	299.0x, 299.8x, and 299.9x (excluded cases with 299.1x or 300.8)	B1	2000–2013, all years used	12	2 to 18	Military Health System
Leslie and Martin (2007)	299.xx	A1	2000–2004, annual	None	0 to 17	Private
Liu et al. (2017)	299.0x and 299.8x	B1	2005–2013, all years used	None	12 to 21	Private
Liu et al. (2019)	299.0x and 299.8x	B1	2005–2013, all years used	None	12 to 21	Private
Mandell et al. (2006)	299.xx	B1	1994–1999, annual	None	0 to 21	Fee-for-service Medicaid
Mandell et al. (2008)	299.00, 299.8, and 299.9	A1	2001	None	0 to 21	Medicaid
Mandell et al. (2010)	299, 299.0x, 299.1x, and 299.8x	C1	2004	9	0 to 21	Medicaid
Mandell et al. (2012)	299.0x, 299.8x, and 299.9x	B2	May 2003–October 2003	None	5 to 21	Medicaid
Mandell et al. (2016)	299.xx	A1	2008–2012, all years used (monthly prevalence estimates)	None	0 to 21	Private
Mandell et al. (2019)	299.xx	B1	2008–2012, all years used	None	0 to 21	Private
Matone et al. (2012)	299.xx	A1	2002–2007, all years used	10	3 to 18	Medicaid
McDermott et al. (2008)	299.0x, 299.8x, and 299.9x	A1	2003	12	1 to 17	Medicaid

Study	ICD-9/10-CM codes used to include or exclude ASD cases (exclusion criteria in parentheses)	Type of algorithm[a]	Years of data used for case ascertainment	Continuous enrollment requirement (months)	Age range (years)	Type of health plans or data source
Nathenson and Zablotsky (2017)	299.x	C2	2000–2013, all years used	12	16 to 23	Private
Oswald and Sonenklar (2007)	299.xx	A1	2002	None	0 to 20	Private
Peacock et al. (2012)	299.0x and 299.8x	C3	2003–2005, all years used	11	1 to 17	Medicaid
Peng et al. (2009)	299.xx and 330.8	A1	1998–2004, all years used	None	0 to 20	Medicaid
Rubenstein and Bishop (2019)	299.0x, 299.8x, 299.9x, F84.0, F84.5, and F84.9	B1	2008–2018, all years used	None	≥ 21	Medicaid
Rubin et al. (2009)	299.0x, 299.8x, and 299.9x	A1	2001	None	3 to 18	Medicaid
Saloner and Barry (2019)	299.xx	B3	2009–2013, all years used	None	0 to 18	Private & state employee PPO plans

ASD autism spectrum disorder, *HMO* health maintenance organization, *ICD-9-CM* International Classification of Diseases, Ninth Revision, Clinical Modifications, *ICD-10-CM* International Classification of Diseases, Tenth Revision, Clinical Modifications

[a]Type of algorithm: (A1) No second claim needed; first claim in any position, (A2) At least one claim in a primary diagnosis field is required, (B1) 2 or more claims, separate days/encounters, (B2) 2 or more claims, separate days/encounters, both in first field, (B3) 2 or more claims, separate days/encounters, at least one in first field, (C1) 2 or more claims on separate days/encounters or 1 inpatient claim, (C2) 2 or more claims in first position on separate days/encounters or 1 inpatient claim

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