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Recognition of clinical characteristics for population-based surveillance of fetal alcohol syndrome

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Abstract

Background: The diagnosis of fetal alcohol syndrome (FAS) rests on identification of characteristic facial, growth, and central nervous system (CNS) features. Public health surveillance of FAS depends on documentation of these characteristics. We evaluated if reporting of FAS characteristics is associated with the type of provider examining the child.

Methods: We analyzed cases aged 7–9 years from the Fetal Alcohol Syndrome Surveillance Network II (FASSNetII). We included cases whose surveillance records included the type of provider (qualifying provider: developmental pediatrician, geneticist, neonatologist; other physician; or other provider) who evaluated the child as well as the FAS diagnostic characteristics (facial dysmorphology, CNS impairment, and/or growth deficiency) reported by the provider.

Results: A total of 345 cases were eligible for this analysis. Of these, 188 (54.5%) had adequate information on type of provider. Qualifying physicians averaged more than six reported FAS characteristics while other providers averaged less than five. Qualifying physicians reported on facial characteristics and developmental delay more frequently than other providers. Also, qualifying physicians reported on all three domains of characteristics (facial, CNS, and growth) in 97% of cases while others reported all three characteristics on two thirds of cases.

Conclusions: Documentation in medical records during clinical evaluations for FAS is lower than optimal for cross-provider communication and surveillance purposes. Lack of documentation limits the quality and quantity of information in records that serve as a major source of data for public health surveillance systems.

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Keywords

clinical diagnosis; diagnostic characteristics; fetal alcohol syndrome; public health surveillance

1 | INTRODUCTION

Fetal alcohol spectrum disorders (FASD) are conditions with varying degrees of neurocognitive impairments, growth deficiency, and abnormal facial features caused by maternal consumption of alcohol during pregnancy, with fetal alcohol syndrome (FAS) representing the most well known of the FASD conditions (Farag, 2014) with both physical and neurobehavioral criteria. Recent estimates of the prevalence of FAS in the United States range from 0.3–0.8 per 1,000 children ages 7–9 years in a record-based multisite surveillance program (Fox et al., 2015) to 6–9 per 1,000 children using active case ascertainment among schoolchildren in a single representative community (May et al., 2014). Some of this wide variation in prevalence estimates may be attributed to clinicians not recognizing the key characteristics of FAS and subsequently not documenting these characteristics in medical records, which serve as the primary data sources for records-based surveillance (Fox et al., 2015). It is important also to note that most children who are adversely affected by prenatal exposure to alcohol do not present with the physical characteristics of FASD such as dysmorphic facial features, which accounted for less than 20% of exposed children in a recent prospective study (Kuehn et al., 2012).

Many types of healthcare providers evaluate children for FAS in a wide variety of clinical settings. In an effort to assist these providers, specific criteria have been developed to describe and define the elements required for diagnosis, most recently in updated clinical guidelines (Hoyme et al., 2016). However, the persistence of lower prevalence estimates in records-based surveillance studies compared to active case ascertainment suggests that many children with FAS are not diagnosed or are misclassified into other diagnostic categories, which can produce inaccurate estimates of FAS prevalence (Astley & Clarren, 2000; Chasnoff, Wells, & King, 2015).

The accuracy and precision of a surveillance program depends on the quality of data it obtains (National Birth Defects Prevention Network, 2014). If sources of potential cases are missed, such as clinics in which children with possible FAS are evaluated and diagnosed, the ultimate result is an artificially low prevalence. In addition, if critical data in records being abstracted are incomplete or absent altogether, the information necessary for determination of case status is missing and results in a lower prevalence estimate.

In this report, we examine differences in documentation of FAS features in medical records among healthcare providers from a recently completed population-based surveillance program for FAS. The goals were to determine which healthcare providers were evaluating children for FAS, to compute the frequencies with which clinical features and measurements were reported by providers in medical records, and to evaluate documentation of clinical information indicative of FAS by type of provider which in turn could facilitate records-based surveillance.

2 | METHODS

The Fetal Alcohol Syndrome Surveillance Network II (FASSNetII) was a population-based surveillance system that collected standardized information from multiple record sources on 7- to 9-year old (birth years 2001–2003) children evaluated for FAS (O'Leary et al., 2015). Cases were obtained from Arizona, seven counties in the Denver metro area of Colorado (Adams, Arapaho, Boulder, Broomfield, Denver, Douglas, and Jefferson counties), and nine counties in western New York (Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Monroe, Niagara, Orleans, and Wyoming counties). A full description of the FASSNetII methodology and the case classification algorithm has been reported previously (O'Leary et al., 2015). The surveillance system included all children living in the catchment areas during 2010 with a date of birth between January 1, 2001, and December 31, 2003. Data were abstracted from medical records by trained abstractors.

Medical record abstraction for FASSNetII included data for specific clinical abnormalities in three domains: facial dysmorphology, central nervous system (CNS) conditions, and growth. There were five characteristics in the facial dysmorphology domain (abnormal facial features, thin or narrow upper lip, abnormal philtrum, short palpebral fissures, and palpebral fissures less than the 10th percentile). The characteristic "abnormal facial features" reflected clinicians' statements that the child had abnormal facial features consistent with a diagnosis of FAS. There were four characteristics in the CNS domain (attention deficit disorder or attention deficit hyperactivity disorder [ADD/ADHD], microcephaly, developmental delay, and intellectual disability) and one in the growth domain (growth deficiency). Abstraction included coding of distinct clinical features within each domain representing 10 unique characteristics. Data were not mutually exclusive and were coded as present when specific qualifying language or measurement was noted in the record. Table 1 presents a detailed description of qualifying criteria for each characteristic. Clinical characteristics were considered present when there was a qualitative statement in the medical record or specific documentation of their appearance, absent if the provider documented absence of the characteristic and "not reported" when there was no mention or insufficient notation of the characteristic in the clinical visit note. Three characteristics (palpebral fissures less than the 10th percentile, microcephaly, and growth delay) were considered present when numerical measurement was reported or calculated to be less than the 10th percentile by standards (O'Leary et al., 2015). Developmental delay included a third category of "insufficient documentation" to demonstrate that providers only reported a single domain from a standardized developmental test.

Case definitions of confirmed and probable FAS were classified through the FASSNetII computed algorithm that consolidates all individual visit data entries accumulated from multiple record sources for each case using clinical criteria in the three domains (O'Leary et al., 2015). Confirmed cases contained documentation of clinical features in all three domains; probable cases contained documentation of features for facial dysmorphology plus one other domain. The remaining cases were pending, as they contained insufficient data to meet the previously stated case definitions. We included pending cases in these analyses because one of the purposes of this manuscript was to determine the frequency with which practitioners accurately document FAS clinical information and excluding these cases would

skew the analysis toward cases with documentation of more features. We only included pending cases for which there was either an FAS or other in utero alcohol exposure diagnosis code listed in the visit. Although such cases might not have enough evidence for case inclusion/exclusion criteria, their records contain valuable information about documented features.

For the primary analysis, individual visits for each case were grouped by source type and provider type. Source types included general or regional hospitals without pediatrics specialty services regularly offered; clinics and hospitals who provided specialties for diagnosing FAS including neonatology, developmental pediatrics, and pediatric genetics; other clinics without qualifying providers; and administrative databases such as birth defects registries, hospital discharge data, Medicaid, and vital records. Providers were grouped together as qualifying physicians (i.e., clinicians with specific training in assessing dysmorphic facial features such as developmental pediatricians, geneticists, and neonatologists), all other physicians, and all other nonphysician providers. For each group, data across all entries for each variable were coded as "reported" if any entry recorded either presence or absence, otherwise it was coded as not reported, except for Developmental Delay which had an intermediate "insufficient reporting" category when at least one but fewer than two testing domain results were reported.

Documentation of an FAS diagnosis in the record was noted if the source included the term "FAS," "FAS suspected," or listing of the FASD Diagnostic Categories A or B (Astley, 2004). A diagnosis of Other FASD included documentation of "fetal alcohol effects or FAE,"[1] "fetal alcohol spectrum disorders or FASD," "alcohol-related neurodeve-lopmental disorder or ARND," "alcohol-related birth defects or ARBD," "Partial FAS," or listing of the FASD Diagnostic Categories C through H (Astley, 2004). Other diagnosis included International Classification of Disease, Ninth edition (ICD-9) code 760.71 and all remaining FASD Diagnostic Categories (Astley, 2004). All other cases qualified as "No diagnosis in record" if there was no mention of an FASD diagnosis or it was specified that FASD was ruled out or not present. The average age at last visit was calculated using date of birth and the latest visit date for the source type, average number of features was determined by counting the number of reported features (out of 10), and average number of visits represented the sum of distinct visit dates by source types.

Data analyses were performed using IBM SPSS Statistics 24.0. We conducted bivariable analyses to examine associations between selected characteristics and surveillance site (Arizona, Colorado, New York). Chi-square tests were used to evaluate differences in proportions ($p < .05$). Any observations with unknown or missing responses were excluded.

NOTE

[1] The term "fetal alcohol effects" or FAE is still observed in medical records, but the Institute of Medicine recommended more than twenty years ago that it be replaced by the terms alcohol-related neurodevelopmental disorder (ARND) or alcohol-related birth defects (ARBD) (https://www.cdc.gov/ncbddd/fasd/facts.html; accessed 6/24/2017).

3 | RESULTS

A total of 345 children in FASSNetII were eligible for study. Characteristics of these children are presented by surveillance site in Table 2. Across all sites, there were 130 confirmed, 31 probable, and 184 pending cases by the FASSNetII case classification method (O'Leary et al., 2015) included in the analysis. Over half (192/345, 56%) were from the Arizona site, and overall males accounted for almost 60% of the total. The largest racial/ethnic group overall comprised those identified as non-Hispanic White (30%) and second largest those identified as American Indian or Alaska Native (23%) followed by Hispanic (16%) and non-Hispanic Black (12%). Maternal history of alcohol use was documented for 66% of all children. Differences among sites were identified for algorithm case status, clinical review case status, race/ethnicity, and maternal history of alcohol use.

We report selected characteristics of the 345 children in FASSNetII by surveillance source type in Table 3. In this table, individual children could be included in more than one column (source type), thus no statistical tests were done. With respect to case status in the source types, the majority reported from clinics or hospitals with specialties (113/173, 65%) and other clinics (70/93, 77%) were confirmed or probable cases, while confirmed/probable cases from general and regional hospitals (55/149, 37%) and administrative sources (50/143, 35%) were each less than 40%. Children with the diagnosis of FAS or other FASD mentioned in the record were 67% or more in clinics or hospitals with specialties (116/173, 67%) or other clinics (72/93, 77%) and less than 50% in general or regional hospitals (73/149, 49%) or administrative sources (7/143, 5%). The percent of children for which a qualifying provider was included in the record was 60% or more in general and regional hospitals (91/149, 61%) and clinics or hospitals with specialties (144/173, 83%), and under 37% in other clinics (33/93, 36%) and administrative sources (5/143, 4%). The documentation of maternal alcohol use was similar across three source types, ranging from 70% to 81%, while in administrative sources it was 55%. With respect to the diagnostic characteristics in Table 3, the average age of last visit was almost eight years in other clinics, while the other sources averaged five years or less. The average number of features listed was almost seven in clinics or hospitals with specialties, close to five in general and regional hospitals and other clinics, while in the administrative sources it was close to two. Finally, the average number of visits at other clinics was over 13, while in the other source types the averages were five visits or fewer.

Of the 345 children in FASSNetII eligible for study, 188 (55%) had documentation of FAS diagnosis indicated in records as well as adequate information in their recorded visits for the type of provider; data for the remaining 157 were excluded from the analysis. Comparison between cases included and excluded from analysis demonstrated that those cases excluded had an overall paucity of reportable information with a much higher proportion of cases classified as pending and a much larger proportion without any documentation of maternal alcohol use reported thereby ensuring the analysis was not skewed toward a lack of documentation. As reported in Table 2, the 188 children included 41% of the 192 eligible from AZ, 59% of the eligible 63 from CO, and 81% of the eligible 90 from NY. In Table 4, we display selected diagnostic characteristics reported (or not) among children seen by three provider types, as well as the number of features reported. As in Table 3, individual children

could have been seen by more than one provider type, thus no statistical tests were done. A total of 121 of the 188 (64%) were seen by qualifying physicians, 43% by other physicians, and 24% by other providers. Qualifying physicians averaged more than six reported features, while other physicians and other providers each averaged less than five features. With respect to facial characteristics, qualifying physicians reported on them for 59% of children or more (ranging as high as 84%), while other physicians and providers reported for 54% or less. For CNS characteristics, presence or absence of developmental delay was reported by qualifying physicians for 89% of children, while the other providers reported on 65% or less. Other physicians and providers reported about ADD or attention deficit hyperactivity disorder (ADHD) in 40% or more of children, while qualifying physicians provided information for 18%. Similarly, other physicians reported on intellectual disability in 16% −20% of children, while qualifying physicians did so for 10%. Reporting presence or absence of microcephaly was similar across providers, ranging from 58% to 67%. All three provider groups reported growth information for 100% of children. And finally, qualifying physicians reported on all three of the domains in 97% of children, while other physicians and other providers reported all three in 65% and 62% of children, respectively.

Qualifying physicians will typically see children who are referred by other providers and could possibly be reporting more characteristics based on previous information reported by other physicians and providers. While we cannot completely rule out that qualifying physicians may have had information from previous visits influencing their documentation, we were able to compare whether or not those cases who saw providers in multiple categories differed with respect to the characteristics reported. Only 29% of cases (54/188) had data in more than one category of provider. Of those, 28 saw qualifying physicians and other physicians, 6 saw qualifying physicians and other providers, and 4 cases saw all three provider categories. We used a pairwise *t* test to compare groups and found no mean differences for number of features reported (data not shown). In the 28 cases with qualifying and other physicians, the mean number of features reported was identical at 6.14. The six cases with qualifying physicians ($M = 7.7$) and other providers reporting ($M = 6.7$) differed by one. Last, the four cases with all three provider groups demonstrated no differences in the three pairwise comparisons *(*$M = 7.50$ for qualifying physicians; $M = 7.00$ for other physician; and $M = 5.50$ for other provider).

4 | DISCUSSION

Despite the availability of diagnostic guidelines, diagnosis of FAS and documentation of this diagnosis in the medical record continues to be a challenge. The data we report suggest that much of the critical information for making the diagnosis of FAS is not being documented by the providers who are evaluating children for possible FAS and making the diagnosis. To facilitate a diagnosis of FAS, it is important for all healthcare providers to have knowledge of the cardinal features of the disorder, and if they do not believe themselves qualified to make the diagnosis of FAS, providers can collect the data needed for a comprehensive evaluation by a provider familiar with FAS. A previous survey of practicing primary care pediatricians found that they were almost universally aware of the clinical presentation of FAS, but that only about half of them were prepared to make the diagnosis and about a third were prepared to manage and coordinate treatment (Gahagan et al., 2006). Similar results

were found in a survey of Spanish and Italian neonatologists and pediatricians (Vagnarelli et al., 2011).

The basic framework of comprehensive diagnostic guidelines for FAS has been available for almost 20 years. Following the initial publication of FAS diagnostic categories and features by the Institute of Medicine (IOM) (Stratton, Howe, & Battaglia, 1996), Astley and Clarren developed the 4-digit scoring system to use more objective criteria than were available at that time, and this system subsequently underwent two revisions (Astley, 2004; Astley & Clarren, 1997, 2000). In 2005, Hoyme et al. proposed diagnostic guidelines based on the IOM criteria and designed for use in clinical pediatric practice (Hoyme et al., 2005). This same year saw the publication of guidelines for Canadian physicians (Chudley et al., 2005). These revisions were timely, as reports from some parts of the world suggested that most health professionals had a limited understanding of the key features of the disorder (Payne et al., 2005). There are limited data to indicate that diagnostic guidelines have had an impact on clinical practice. For example, a survey of clinics in Canada found that 74% were using the new diagnostic recommendations in the 2005 Canadian guidelines (Clarren, Lutke, & Sherbuck, 2011). However, this same evaluation reported that less than half of the clinics had a full staff of health professionals on site to make the diagnosis.

Some providers receive specialized training in the recognition and diagnosis of children with the physical features of FAS, such as geneticists/dysmorphologists and developmental pediatricians. This training includes the recognition of major and minor structural abnormalities and the application of anthropometric measurement techniques for assessment of growth and craniofacial features. Thus, these clinicians are often the providers to whom children suspected to have had prenatal alcohol exposure are referred. Previous investigations suggest, however, that pediatricians with training in recognition of FAS features can make the diagnosis with similar accuracy to expert FAS diagnosticians (Jones et al., 2006). Even with training in and knowledge of FAS diagnostic criteria, many providers who might suspect a diagnosis are reluctant to initiate a subspecialty referral over concerns regarding stigmatization and loss of patient physician rapport (Elliott, Payne, Haan, & Bower, 2006).

Some physical features diagnostic for FAS that can be assessed quantitatively include height, weight, head circumference, philtrum length, and palpebral fissure length. They may also be reported qualitatively, using descriptors such as “short palpebral fissures,” “abnormal philtrum,” or “abnormal facial features.” In our data, the qualifying physicians reported about philtrum appearance and palpebral fissure length in 59%−84% of children evaluated, while other providers reported in 18%−54% of children depending on the specific characteristic. We found that records of visits to some providers frequently failed to note even a qualitative assessment of philtrum appearance or palpebral fissures, with 54% of children containing reports about the philtrum, and palpebral fissure length described as short ranging from 18% to 38%. This is consistent with one post-training survey that found that even after training on assessing patients for FAS, many providers of care to high-risk patients reported that they were using growth charts to evaluate height/length and weight for age but did not use lip philtrum guides or palpebral fissure length measurements (Evans, Tenkku, Kennedy, Zoorob, & Rudeen, 2014).

Deficiencies in growth and head circumference can be evaluated using simple, available tools such as a measuring tape and scale. The measurement of height, weight, and head circumference is standard practice for pediatric visits (Sniderman, 2010); the American Academy of Pediatrics guidelines recommend measurement of height/length and weight at every visit and of head circumference at each well child visit from birth through 24 months (American Academy of Pediatrics, 2010).

In our data, information concerning the child's physical growth was reported in 100% of children. The presence or absence of microcephaly was consistently reported for two thirds of children.

The behavioral symptoms of FAS, such as ADD/ADHD and developmental delay, are evaluated through clinical assessment of the child's behaviors in conjunction with input from parents, teachers, and other caregivers. In our data, information about ADD/ADHD was not reported by most providers (58%−82%), which likely reflects the dependence of the FASSNetII surveillance programs on medical records as a major source of data. Information on developmental delay was more consistently reported across provider types. We found that 80% or more of children did not have reported information about intellectual disability, which again could reflect lesser access in FASSNetII to records other than those of healthcare providers.

4.1 | Strengths/limitations

This study has a number of strengths. The data have been generated by a multisite, population-based surveillance system in which the same methodology was applied across sites as described previously (O'Leary et al., 2015). A key component of FASSNetII was the implementation of a Clinical Review Committee to evaluate the case status of each potential case as confirmed or probable by reviewing the abstracted data on each of the cases presented to the committee, regardless of whether an FAS diagnosis was stated in the records. Finally, the 345 children we studied provide a robust sample size for examining questions on the diagnosis of FAS in the community.

There are a few limitations of these data. There were some differences among sites for certain characteristics such as case status, race/ethnicity, and maternal history of alcohol use that could have affected our results. Information on maternal alcohol consumption during pregnancy was not always available in the medical records and was not required to meet the case definition for FAS. The differences among sites for both the algorithm and clinical review case status categories likely reflect some variation from site to site in the sources used for case finding and abstraction as well as the sequencing of case finding among the sources accessed by a given surveillance site.

In addition, this study does not provide any perspective on those children with FAS who were not evaluated at sources to which we had access. Although a variety of clinical sources were included, and the record review and data collection were intended to be a comprehensive ascertainment of all possible cases in these communities, it is limited to those children who had access to clinical services at available sources. The percentage of records with no recorded data could have been biased upward if FAS diagnosis was not the

primary purpose for these visits, but we had no way to identify which visits were referrals for diagnosis of FAS and which were for another purpose. Another limitation of these data is that some providers could have failed to report data for a given diagnostic characteristic because the information had already been included in a child's record by another provider. We have no way to determine the frequency with which this could have occurred. Finally, our focus on the diagnosis of FAS might have affected the surveillance data. For example, some children referred to certain providers for pressing behavioral or cognitive concerns might not have been referred in turn to a qualifying provider despite suspicions about possible effects of alcohol. We acknowledge that FAS is only part of the full spectrum of FASD, which also includes ARND, in which individuals can have intellectual disability and behavioral and learning issues, and ARBD involving medical problems we did not consider.

4.2 | Conclusions/implications

The conclusions that emerge from this study are as follows:

1. In this FAS surveillance data set, the documentation in medical records during clinical evaluations for FAS is lower than optimal for cross-provider communication and surveillance purposes.
2. For dysmorphic facial features characteristics that are required for making the diagnosis of FAS, qualifying providers are more apt to report the required information.
3. Given that qualifying providers are not the only providers who evaluate children with potential FAS or make the diagnosis of FAS, there seems to be a need to improve documentation practices to facilitate communication across providers (both diagnostic and treatment) as well as allow for public health surveillance of FAS.

There are several implications of these findings for surveillance. Without the data necessary to determine if children have FAS or not, FAS surveillance projects will not identify all potential cases of this condition. Therefore, it appears that low prevalence estimates in many public health surveillance programs for FAS could, at least in part, be the result of the lack of the essential data in the medical records on which these programs rely. Case finding using the case classification algorithm by surveillance systems and in databases of electronic health records has the potential to ensure that a higher proportion of FAS cases are provided with services they need. However, our results clearly demonstrate that the information necessary to identify cases by these methods is often not indicated in records by the providers who are evaluating children for FAS.

From a clinical perspective, these results suggest a continuing need to train physicians and other healthcare providers and increase awareness of the importance of recording information whenever a child is suspected of having FAS. Despite efforts to educate physicians and other providers about FAS and the importance of early intervention, absence of critical information in the medical records of at-risk children limits their identification solely from the medical record. Public health programs for diagnosis and treatment of children with FAS that combine information from multiple sources such as school records,

early intervention programs and medical sources may prove especially useful and are worthy of further investigation.

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Table 1

Definitions of the 10 FAS characteristics across the three domains

Characteristic	Qualifies	Does not qualify
Abnormal facial features consistent with FAS	**• Appears to have, somewhat, mild, slight, some, minor, relatively, subtle (features). (Statement should also mention FAS.)** **• Many characteristics of FAS (only if this is marked in the HEENT or face part of the examination)** **• Minor stigmata of FAS, some facial features consistent with FAS or some facial features associated with the fetal alcohol spectrum of effects** **• Baby with features of FAS or mild FAS** **• Facial manifestations of individuals with FAS** **• Has typical FAS morphology**	**• Abnormal facies** **• FAS facial features questioned** **• Minor dysmorphic features with no recognizable syndrome** **• Slight stigmata of FAE or features suggestive of FAE** **• Subtle facial features** **• Unusual facial appearance** **• Face is mildly dysmorphic**
Thin or narrow upper lip	**• Small upper lip** **• Attenuated upper lip** **• Indistinct Vermillion border** **• Poorly defined cupid's bow** **• Vermillion is somewhat diminished** **• Mildly undermodeled border of upper lip** **• Vermillion/lip rating 4 or 5 (IV or V)** **• Astley scale = 4 or 5 (with mention of Vermillion or lip)** **• Likert scale = 4 or 5 (with mention of Vermillion or lip)** **• Lip/vermillion guide value = 4 or 5**	**• Short upper lip** **• Astley scale < 4 (lip)** **• Likert scale < 4 (lip)** **• Vermillion/lip guide value <4**
Abnormal Philtrum	**• Poorly formed philtrum** **• Minimal philtrum** **• Smooth philtral columns** **• Philtral Rating 4 or 5 (IV or V)** **• Smooth upper lip (equivalent to "smooth philtrum")** **• Astley scale = 4 or 5 (with mention of philtrum)** **• Likert scale = 4 or 5 (with mention of philtrum)** **• Philtrum Guide Value = 4 or 5**	**• Short philtrum** **• Likert scale <IV (philtrum)** **• Astley scale <4 (philtrum)** **• Likert scale <4 (philtrum)** **• Philtrum Guide Value <4**
Short palpebral fissures	• Appears to have somewhat narrow palpebral fissures **• Eyes appear small** **• Narrow palpebral fissures or "PF"**	• Mild widening of inner canthus **• Broad inner canthus** **• Telecanthus**
Palpebral fissures <≤ 10th percentile	• Measurements ≤10th percentile at birth or any age	
Characteristic	Qualifies	Does not qualify
ADD or ADHD	• "ADD" or attention deficit disorder **• "ADHD" or attention deficit hyperactivity disorder**	
Microcephaly	**• Decreased cranial size at birth** **• Microcephaly** **• Cerebellar Hypoplasia** **• Partial or complete agenesis of the corpus callosum** **• Head circumference < 10th percentile at birth or any age**	
Developmental delay	**• Minimum of two out of ten domains reported for either presence or absence • ≥2 domains that are ≥1 standard deviation below the mean** **• Clinical diagnosis of a developmental disorder** **• Documentation of Global Developmental Delay**	
Intellectual disability	**• Intellectual delay** **• Low cognitive function** **• Mental retardation (older records)** **• Standardized IQ > 2 standard deviations below the mean**	
Growth delay	• Weight or height ≤ 10th percentile for age **• Weight or height corrected for gestational age < 10th percentile** **• Weight for height ≤ 10th percentile**	

Note. FAS, fetal alcohol syndrome; FAE, fetal alcohol effects; IQ, intelligence quotient; HEENT, head, ears, eyes, nose, and throat.

Table 2

Selected characteristics and univariate results of 345 children in FASSNetII

	All sites (*n* = 345)		Arizona (*n* = 195)		Colorado (*n* = 63)		New York (*n* = 90)	
	N	**%**	***N***	**%**	***N***	**%**	***N***	**%**
Algorithm case status[a]								
Confirmed	130	37.7	52[b]	27.1	21	33.3	57[b]	63.3
Probable	31	9.0	15	7.8	8	12.7	8	8.9
Pending	184	53.3	125[b]	65.1	34	54.0	25[b]	27.8
Clinical review case status[a, c]								
FAS with alcohol exposure	83	24.1	33	17.2	12	19.0	38	42.2
FAS without alcohol	7	2.0	2	1.0	1	1.6	4	4.4
Probable FAS with alcohol	30	8.7	12	6.3	9	41.3	9	10.0
Probable FAS without alcohol	14	4.1	6	3.1	3	4.8	5	5.6
Not an FAS case	35	10.1	17	8.9	5	7.9	13	14.4
Not reviewed	176	51.0	122	63.5	33	52.4	21	23.3
Gender								
Male	205	59.4	115	59.9	39	61.9	51	56.7
Female	140	40.6	77	40.1	24	38.1	39	43.3
Race/ethnicity[a]								
White	103	29.9	32[b]	16.7	27	42.9	44	48.9
Hispanic	55	15.9	31	16.1	16	25.4	8	8.9
Black or African American	41	11.9	8[b]	4.2	6	9.5	27[b]	30.0
American Indian or Alaska Native	79	22.9	73[b]	38.0	3[b]	4.8	3[b]	3.3
Other	14	4.1	6	3.1	5	7.9	3	3.3
Unknown	53	15.4	42[b]	21.9	6	9.5	5[b]	5.6
Maternal history of alcohol use[a, d]								
Yes	229	66.4	115	59.9	48	76.2	66	73.3
No	116	33.6	77	40.1	15	23.8	24	26.7
Inclusion								
Table 3 sources[e]	345	100.0	192	100.0	63	100.0	90	100.0
Table 4 providers[f]	188	54.5	78	40.6	38	58.7	73	81.1

Note. FAS, fetal alcohol syndrome; FASSNetII, Fetal Alcohol Syndrome Surveillance Network II.

[a] Chi-square significant at $p < .05$.

[b] Cell standardized residuals > |2|.

[c] Two FAS rows, two probable FAS rows, and two rows for not an FAS case, and not reviewed were collapsed to avoid issues with small expected frequencies.

[d] documentation in any abstracted record of maternal alcohol use during the index pregnancy.

[e] Table 3 sources refers to surveillance source types shown in Table 3 including general or regional hospital, clinic or hospital with specialties, other clinic, and administrative source.

[f] Table 4 providers: provider types shown in Table 4 including qualifying physician, other physician, and other provider, as described in detail in Table 4.

Table 3

Selected positive characteristics by source type for 345 children in FASSNetII

	FASSNetII children, *N* = 345							
	General or regional hospital		Clinic or hospital with specialties		Other clinic[a]		Administrative source	
	N	Column %	*N*	Column %	*N*	Column %	*N*	Column %
Total Children	149		173		93		143	
Algorithm case status								
Confirmed	47	31.5	89	51.4	65	69.9	44	31.0
Probable	8	5.4	24	13.9	7	7.5	6	4.2
Pending	94	63.1	60	34.7	21	22.6	93	65.0
Diagnosis mentioned in record								
FAS	58	38.9	93	53.8	65	69.9	6	4.2
Other FASD	15	10.1	23	13.3	5	5.4	1	0.7
Other diagnosis	28	18.8	10	5.8	4	4.3	135	94.4
None	48	32.2	47	27.2	19	20.4	1	0.7
Maternal alcohol use documented[b]								
Yes	106	71.1	122	70.5	75	80.6	79	55.2
No	43	28.9	51	29.5	18	19.4	64	44.8
Providers								
Qualifying provider included[c]	91	61.1	144	83.2	33	35.5	5	3.5
No qualifying providers	41	27.5	29	16.8	57	61.3	121	84.6
No provider type listed	17	11.4	0	0.0	3	3.2	17	12.0
	Mean	***SD***	**Mean**	***SD***	**Mean**	***SD***	**Mean**	***SD***
Diagnostic characteristics								
Average age at last visit in years	3.56	3.21	4.65	3.17	7.83	2.07	2.63	2.91
Average number of features listed	5.42	2.12	6.94	1.92	4.91	1.98	2.27	.98
Average number of visits at source	5.06	5.18	5.41	5.12	13.16	8.10	1.59	.97

Note. FAS, fetal alcohol syndrome; FASD, fetal alcohol spectrum disorders; FASSNetII, Fetal Alcohol Syndrome Surveillance Network II.

[a] Early intervention program, primary care, psychiatry/psychology, unknown source type.

[b] documentation in any abstracted record of maternal alcohol use during the index pregnancy.

[c] Developmental Pediatrician, Geneticist, or Neonatologist.

Table 4

Selected diagnostic characteristics and univariate results of FASSNetII recorded visits with documentation of FAS diagnosis by pro-vider type among 188 children[a]

	Qualifying physician[b]		Other physician[c]		Other provider[d]	
	N	**Column %**	***N***	**Column %**	***N***	**Column %**
Total number of children with visits by physician type	121	64.4	80	42.6	45	23.9
Facial dysmorphology						
Abnormal facial features						
Reported	72	59.5	30	37.5	16	35.6
Not reported	49	40.5	50	62.5	29	64.4
Thin or narrow upper lip						
Reported	92	76.0	39	48.8	22	48.9
Not reported	29	24.0	41	51.3	23	51.1
Abnormal philtrum						
Reported	102	84.3	43	53.8	24	53.3
Not reported	19	15.7	37	46.3	21	46.7
Short palpebral fissures						
Reported	71	58.7	30	37.5	8	17.8
Not reported	50	41.3	50	62.5	37	82.2
Palpebral fissures < 10th percentile						
Reported	93	76.9	27	33.8	15	33.3
Not reported	28	23.1	53	66.3	30	66.7
Central nervous system						
ADD or ADHD[e]						
Reported	22	18.2	34	42.5	18	40.0
Not reported	99	81.8	46	57.5	27	60.0
Microcephaly						
Reported	81	66.9	52	65.0	26	57.8
Not reported	40	33.1	28	35.0	19	42.2
Developmental delay[f]						
Reported	108	89.3	52	65.0	6	13.3
Not reported	13	10.7	28	35.0	39	86.7
Insufficient documentation	6		2		1	
Intellectual disability						
Reported	12	9.9	13	16.3	9	20.0
Not reported	109	90.1	67	83.8	36	80.0
Growth						
Reported	121	100.0	80	100.0	45	100.0
Not reported	0	0.0	0	0.0	0	0.0
All domains listed						
No	4	3.4	28	35.0	16	38.1

	Qualifying physician[b]		Other physician[c]		Other provider[d]	
	N	**Column %**	***N***	**Column %**	***N***	**Column %**
Yes	115	96.6	52	65.0	26	61.9
	Mean	*SD*	Mean	*SD*	Mean	*SD*
Diagnostic characteristics						
Average number of features	6.35	1.50	4.98	2.11	4.18	2.15

Note. FAS, fetal alcohol syndrome; FASSNetlI, Fetal Alcohol Syndrome Surveillance Network II; ADD, attention deficit disorder; ADHD, attention deficit hyperactivity disorder; *SD,* standard deviation.

[a] The remaining cases in the data set had undocumented practitioner data or practitioners were of unknown specialty.

[b] Developmental Pediatrician, Geneticist, or Neonatologist.

[c] Psychiatrist, neurologist, or other physician type.

[d] Nonphysician provider.

[e] ADD or ADHD was only documented if positive in the medical record, therefore not reported likely includes “no” responses.

[f] developmental delay includes either a diagnosis of global delay or documentation of 2 of 9 possible domains. Insufficient documentation includes cases documenting only1domain. These data were considered missing.