FETAL ALCOHOL SYNDROME (J KABLE, SECTION EDITOR)



Advancing Recognition of Fetal Alcohol Spectrum Disorders: the Proposed DSM-5 Diagnosis of "Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)"

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Abstract Fetal alcohol spectrum disorders (FASD) are a surprisingly common, yet under-identified set of lifelong neurodevelopmental disabilities with substantial economic and social costs—and high rates of debilitating secondary conditions. An advance in the field of FASD is a proposed diagnostic category included in the 2013 Diagnostic and Statistical Manual for Mental Health Disorders (DSM-5): "Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure" (ND-PAE). With clinical guidelines to inform its use, appropriate recognition of ND-PAE can allow wider identification of individuals impacted by alcohol's teratogenic effects. Accurately recognizing that a diagnosis of ND-PAE might apply can inform health and mental health providers about when to refer for specialty assessment, and suggest when and how to adapt usual treatments or access tailored interventions. This paper explains the evolution in diagnostic terms, discusses clinical use of ND-PAE, explores dilemmas, and presents ideas for "FASD-informed care" for individuals who meet proposed ND-PAE criteria.

Keywords FASD · Fetal alcohol spectrum disorders · Fetal alcohol syndrome · Alcohol-related neurodevelopmental disorder · Partial fetal alcohol syndrome · Alcohol-related birth defects · Treatment · Diagnosis · Diagnostic techniques and procedures · Nomenclature · Prenatal exposure delayed

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effects · Teratogens · Children · Child, preschool · Adolescents · Adults · Central nervous system · Intervention studies · Self-regulation · Behavior, adaptive · Disabilities, developmental · Cognition · Phenotype · Birth defects

Introduction

A compelling body of basic and human research has documented the teratogenic effects of prenatal alcohol exposure (PAE). Describing the full range of clinically concerning effects associated with PAE, the term "fetal alcohol spectrum disorders" (FASD) [1, 2] was accepted in 2004 by consensus of governmental, research, and advocacy organizations. The term FASD refers to a set of lifelong neurodevelopmental disabilities with strikingly high rates of secondary problems in daily function [3].

Recent estimates of FASD prevalence, using in-school active case ascertainment studies, are as high as 2-5 % in the USA and some Western European countries [4]. Estimates do vary depending on the methodology used. In clinical settings, recent data indicates that diagnoses of conditions in the category of FASD are likely being missed or misdiagnosed [5•]. FASD, and the effects of PAE, are a global health problem. Though difficult to estimate, very high economic and social costs of FASD have been documented in multiple countries [6-8]. Caregivers raising children with FASD have many unmet important needs [9]. These caregivers also show significant parenting stress [10], at levels higher than those raising children with autism [11]. Over the lifespan, caregivers and individuals with FASD interact with a wide range of service systems, but frequently encounter barriers. Most centrally, providers lack knowledge about FASD [12•].

Use of the term FASD has improved community awareness of impairments often seen in those affected by PAE, even when obvious physical signs are absent. But FASD is



a non-diagnostic term. Nomenclature and diagnostic methods are evolving in the field of FASD, as in the fields of ADHD [13, 14], intellectual disabilities [15], and mood disorders [16].

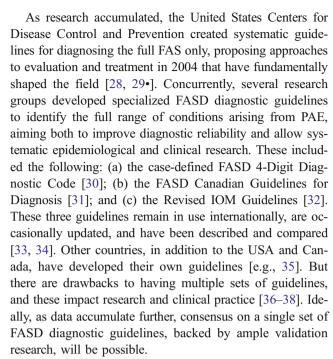
An important recent step in evolution of diagnostic nomenclature is the introduction of a proposed diagnostic category included in the Diagnostic and Statistical Manual for Mental Health Disorders (DSM-5): Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) [17•]. Currently, ND-PAE is contained in Section III of the DSM-5 as a "condition in need of further study." With clinical guidelines to inform its use, appropriate recognition of ND-PAE can allow wider identification of individuals impacted by alcohol's teratogenic effects. This can encourage momentum toward better access to services. The ultimate aim is to provide FASD-informed care [18•], with more appropriate treatment of affected individuals, in order to reduce troubling secondary conditions—and to lighten caregiver burden.

This paper describes the evolution in diagnostic terms and practices in the field of FASD, and explains why more accessible diagnosis is needed. Proposed diagnostic criteria for ND-PAE, clinical guidelines, and current dilemmas in use of ND-PAE are discussed. The way in which the proposed ND-PAE diagnostic process relates to FASD specialty clinic team assessments is clarified. Finally, brief information is presented regarding FASD-informed care in treatment and other settings, which may apply when the diagnosis of ND-PAE is given.

Evolution in Diagnostic Terms and Practices in the Field of FASD

While there is historical mention of alcohol's adverse impact on child outcome and fertility [19], features of what has come to be known as fetal alcohol syndrome (FAS) were recognized only about 40 years ago [20, 21]. Several reviews have traced how diagnosis of alcohol's teratogenic effects has evolved over time [22–24].

Once identified, FAS gained gradual acceptance as a medical condition but was viewed as a rare disorder. Rapidly growing research documented alcohol's harmful teratogenic effects, especially central nervous system (CNS) dysfunction seen as diverse behavior and learning problems. Data suggested the existence of a wider spectrum of effects, beyond FAS, which meant a need to identify and treat a greater prevalence of clinical conditions arising from PAE [25]. Various terms were introduced to describe this wider range of effects [26]. In 1996, the Institute of Medicine (IOM) published a report on diagnosis of a set of conditions that included FAS, but also defined three additional diagnostic categories and provided criteria with increased detail and specificity [27].



The following terms are in current use in the field of FASD. The term "FAS" refers to the established fetal alcohol syndrome with characteristic facial dysmorphology, growth impairment, and CNS dysfunction. The term "pFAS," or partial FAS, refers to individuals with PAE who have some (but not all) physical signs and show CNS dysfunction. The term "ARND," or alcohol-related neurodevelopmental disorder, refers to a group of conditions in which there is PAE paired with CNS dysfunction, without physical signs. The important caveat is that the CNS dysfunction is not well-explained by disorders attributable to the physiological effects associated with postnatal use of a substance, another medical condition, or environmental neglect [27]. There is continuing debate about terms implying causality when pairing PAE with CNS dysfunction [39]. Some FASD diagnostic guidelines have added specialized terms to more precisely describe the range of conditions beyond FAS and pFAS, and to avoid assuming a causal connection [30]. There is also a diagnostic term, "ARBD," or alcohol-related birth defects (such as cardiac anomalies), for use when there is PAE (in the absence of CNS dysfunction) [27]. This term is not often used. Unfortunately, despite general acceptance of these terms, guidelines are often not consulted or prior diagnoses not checked for accuracy. This means that diagnostic reliability is variable.

FASD diagnostic specialty clinic capacity has slowly grown [40], focused mostly on children and adolescents, with clinics evaluating adults recently emerging [41]. Survey data from one clinic system found that caregivers deemed diagnostic services satisfactory and helpful in accessing interventions [42]. Specialized diagnostic clinics have generated important human research data, and investigation of FASD has been lively and challenging [43]. But while a specialized team assessment



process is considered the gold standard for the FASD diagnostic process, clinics offering these services have limited capacity and family access. Clinical experience and international survey of diagnostic clinics [38] ascertained these clinics are challenging to fund, have long waiting lists, cover limited geographic areas, are concentrated in North America, and show considerable variation in diagnostic practice. Relying on a limited specialty clinic system cannot fully address the pressing diagnostic need—and serious societal impact [44]—created by the surprisingly high prevalence of conditions resulting from PAE.

As literature describing FASD has grown, and clinical diagnostic methods sought, there has been a search for a "behavioral phenotype" [45-47]. The goal is to find patterns of observable behavior that present as symptoms that consistently occur together, which define and distinguish a clinical condition with adequate specificity and sensitivity. Prior data analysis and literature review uncovered some patterns [48, 49]. However, because alcohol's teratogenic effects are individually variable, impacted by the pattern and timing of maternal drinking during fetal development, by other risk factors and genetic characteristics of the mother and fetus, and by epigenetic processes—clear-cut consistency in CNS dysfunction across individuals would not be expected [24, 50]. One interesting theory is that the FASD phenotype is a "generalized impairment in processing and integration of information" [51]. The various specialized FASD diagnostic guidelines have solved the problem of identifying CNS dysfunction by requiring testing evidence of three areas of significant functional impairment (e.g., executive function, memory, attention, etc.), but allowing these areas to vary across individuals.

Despite this individual variability in teratogenic alcohol effects, expert consensus from careful synthesis of growing clinical and research data has recently uncovered three "superordinate" categories of CNS dysfunction that fit with current theories and prior data review [52]. These are evidence of impairment in: (a) neurocognitive functioning, (b) behavioral or self-regulation functioning, and (c) adaptive functioning. While not comprising a classic behavioral phenotype, it is now possible to propose a set of diagnostic criteria using these broad categories, and so to define the clinical condition of ND-PAE.

The Need for an Additional, More Accessible Diagnostic Approach

Clinical diagnostic methods must fit into two sets of comprehensive nomenclature systems used by mental health and health care providers, and payors, to define and describe medical and mental health conditions. One system is the International Classification of Diseases (ICD) [53]. This system is currently used worldwide in both its 9th and 10th editions,

but is now in the long process of being updated to its 11th edition (ICD-11). Another system is the Diagnostic and Statistical Manual of Mental Disorders, now in its 5th edition (DSM-5) [17•], which has many new characteristics [54•]. These systems reference each other, evolve with time as research and clinical understanding advance and, to some extent, co-evolve. These systems of nomenclature are important, as they drive research, provider training and practice, mental health funding, and public policy. There are other classification systems that also drive research, such as the Research Domain Criteria [55].

In the ICD-10 nomenclature [53], the only directly relevant terms to conditions within FASD are "fetal alcohol syndrome, dysmorphic" (Q86.0), and "newborn (suspected to be) affected by maternal use of alcohol" (P04.3). Interestingly, there is a maternal code termed "maternal care for (suspected) damage to fetus from alcohol" (035.4XX0). ICD-9 had even more limited terms. Prior to DSM-5, if effects of PAE were noted at all, clinicians using the DSM system were simply referred to the ICD system. Strikingly, the full spectrum of lifelong neurodevelopmental disabilities associated with PAE remained unidentified by both nomenclatures. Because of this, clinicians were forced to describe symptoms, create treatment plans, and bill for services using existing diagnoses that might not adequately characterize the range and pattern of effects of PAE. Insufficient terminology in these nomenclatures has seriously constrained family access to appropriate services.

While FAS may be the most visible clinical condition resulting from PAE, this term is inadequate. Even for those with FAS, the term implies medical problems and does not adequately capture difficulties in mental health and daily life experienced by affected individuals. In many cases, the medical diagnosis of FAS has not prompted multidisciplinary assessment or satisfactory access to services.

Even more importantly, most individuals significantly affected by PAE do not meet criteria for the FAS diagnosis, simply because they do not show physical signs. This means they are not even recognized as having disabilities. Yet, early on, data showed similar types of neuropsychological deficits among those with FAS, and those with heavy PAE but without facial dysmorphology or growth impairment [56]. Without a diagnostic label, the vast majority of individuals affected by PAE have gone unidentified, despite significant functional impairments and often compromised life success. Indeed, a recent clinical study demonstrated that 86.5 % of 156 children and adolescents with an FASD, adopted or in foster care, had never been previously diagnosed or had been misdiagnosed [5•].

Despite these nomenclature problems and difficulties with accessible diagnosis, there has been real progress in recognition of FASD worldwide. For example, in the USA, family advocacy and needs assessment sparked change [44]. A clinical plan of action to reduce adverse outcomes of PAE was



proposed in 2006 [57]. Community and professional FASD education has expanded [58], and some screening systems are in place [59] or under investigation [60]. Clinical interventions have been discussed [9, 61], reviewed [62–64], critiqued [65], and treatment research continues on many levels. A growing number of affected individuals have been identified. But surveys of varied professionals have identified major gaps in knowledge about FASD [66–69]. Because of this, providers have not recognized the disability, or diagnosis has been delayed. Eligibility for services has been constrained and, if available, services have not always been appropriate or possible to maintain [12•].

An additional, more accessible diagnostic approach is needed, using nomenclature and a diagnostic approach that health and mental health providers can more readily use and understand.

A New Diagnostic Term: Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure

To advance clinical care, DSM-5 now includes a proposed diagnostic category using a new clarifying term that encompasses most disabilities associated with PAE. This term is Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure. This term acknowledges the well-documented association of PAE with functional impairment and allows diagnosis based largely on observable learning and behavioral symptoms. FAS, pFAS, and the broader set of conditions in the category of FASD (i.e.., what has been called ARND) can all be included within the rubric of ND-PAE.

It is not necessary to assess physical effects (i.e., growth impairment, facial dysmorphology) to diagnose ND-PAE. However, if that assessment capability is available, proposed diagnostic criteria allow sentinel physical findings to be specified. The specifiers used are ND-PAE "with dysmorphia" or "without dysmorphia."

The combination of deficits in proposed DSM-5 diagnostic criteria for ND-PAE reflect a careful, iterative process of consensus through expert testimony and workgroup efforts [70•]. Criteria were derived from integration of the very large literature on the impact of PAE, described in a recent review [52]. A diagnosis based on the combination of deficits in proposed criteria, *in the presence of prenatal alcohol exposure*, has a high probability of capturing the neurodevelopmental disabilities and functional impairment associated with PAE. Proposed diagnostic criteria for ND-PAE will be the focus of ongoing empirical validation research and have been noted as an advance in the array of neurodevelopmental disorders identified in DSM-5 [71].

Proposed diagnostic criteria for ND-PAE, including how PAE is defined, can be found in Section III of the complete DSM-5 manual [17•]. Importantly, with the introduction of

DSM-5, it is possible now to apply ND-PAE as a specifier for the broader diagnostic term of an "Other Specified Neurodevelopmental Disorder," and so to render a diagnosis. This process is explained below, with guidance for clinicians who use this proposed diagnostic process.

Using Proposed Diagnostic Criteria for ND-PAE: an Overview

Best practices for mental health diagnosis, including use of ND-PAE, are to conduct a careful intake and assessment process, using informed clinical observations, interview, and other available data, adhering to a biopsychosocial framework of case formulation and treatment planning. To use ND-PAE, also necessary is background education on FASD, updated periodically as knowledge in the field rapidly accrues, to recognize and understand ND-PAE [18•, 58]. Venues for FASD education are developing rapidly. Websites directing providers to education are listed just before the reference section.

Using Proposed Diagnostic Criteria for ND-PAE: Prenatal Alcohol Exposure

ND-PAE can *only* be diagnosed when there is evidence of PAE, with a single exception discussed below. Evidence of PAE that is "more than minimal" is currently required for ND-PAE. Clinicians are advised to acquire training in asking about maternal drinking during pregnancy. Training programs are available. Website resources listed just before the reference section can guide the reader to appropriate training.

Convincing information about alcohol use during pregnancy must be gathered. Examples are maternal self-report of alcohol use in pregnancy, medical or other records, or clinical observation. The report of a reliable informant may be acceptable evidence, but only if the informant actually observed drinking during gestation of the individual being evaluated. Inferring that drinking must have taken place because a woman is currently drinking, or was seen drinking at times other than during pregnancy, is not acceptable evidence. At present, "more than minimal" PAE is defined as more than "light drinking." Since drinking can occur prior to pregnancy recognition and/or following pregnancy recognition, both time periods should be assessed. Light drinking is defined as 1 to 13 drinks per month during pregnancy, with no more than two of these drinks consumed on any one drinking occasion [72]. One major issue in using ND-PAE is that records may not include adequate information about amount, pattern, or timing of drinking, so providers must try to collect this information.



Research will further define guidelines for a *clinically concerning* threshold of "more than minimal" exposure, though this is challenging [73]. Given the multiple biological mechanisms through which alcohol produces fetal effects, and the striking variability in drinking patterns and maternal/fetal susceptibility, a *safe* drinking threshold will likely *never* be established. If a biomarker for ND-PAE can eventually be found, this may resolve dilemmas inherent in self-report of PAE and the question of a threshold.

A quirk of diagnosis is that the full FAS *can* be diagnosed in the absence of information on PAE, given research documenting that characteristic facial features are a biomarker of PAE. In these cases, facial features and growth *must* be appropriately assessed. Receiving a diagnosis of FAS means it is likely that an individual meets criteria for "ND-PAE with dysmorphia," even if PAE is not known.

Using Proposed Diagnostic Criteria for ND-PAE: Domains of Functional Impairment

Based on a wealth of data [52], the essential features of ND-PAE are proposed to be evidence of impairment in neurocognitive, behavioral or self-regulation, and adaptive functioning. Impairment can be documented via record review, client or informant report, and/or clinical observations. Psychometric testing can be very helpful. The paper by Mattson and colleagues in the current issue of this journal provides guidance about recommended assessment measures.

Proposed symptoms of ND-PAE occur in a triad of developmental areas. First, there must be impairment in global intellectual performance (IQ) or neurocognitive impairments in any one of the following areas: executive functioning, learning, memory, and visual-spatial reasoning. It is not necessary that intellectual disabilities be present, as the majority of individuals with PAE do not have an intellectual disability even though they may show other signs of CNS dysfunction [74]. Second, impairments in selfregulation must be present and may include impairment in one area of mood or behavioral regulation, attention deficits, or impairment in impulse control. Third, impairments in two areas of adaptive functioning must be present. These must include communication deficits and/or impairment in social communication and interaction. Impairment in daily living (self-help) skills and/or impairment in motor skills may be present. It may be appropriate to defer a diagnosis for children birth to 3 years old. Importantly, though, there is sometimes sufficient evidence to make the diagnosis in a young child. For instance, just over half of children aged birth to 3 years with PAE (or with FAS/pFAS) do show marked developmental delay [75]. Early diagnosis (before age 6 years) is associated with higher odds of more positive outcomes [3]. If young children are diagnosed, early intervention can occur, which takes maximum advantage of neuroplasticity.

Individuals meeting criteria for ND-PAE may experience a number of co-occurring risk factors, including the following: ongoing parental alcohol/substance abuse or dependence; parental mental illness; trauma in the form of exposure to domestic or community violence, neglect or abuse, disrupted caregiving relationships, or multiple out-of-home placements; and lack of continuity in medical or mental health care [76, 77]. Such risk factors impact developmental outcomes, and should be evaluated and taken into account in case formulation and treatment planning.

Disorders That Co-occur or Show Similar Symptoms

A limited number of competing medical conditions, listed in the DSM-5 explanation of ND-PAE, must be ruled out. Referral for a genetic work-up may be important.

Some individuals with ND-PAE may meet criteria for other mental health disorders. Careful consideration is required to decide whether (or not) a co-occurring disorder should be diagnosed. Appropriateness of other diagnoses must be weighed keeping in mind the significant neurocognitive and adaptive function impairment often associated with PAE. These types of impairments are not necessarily found in disorders with similar disruptive behavior symptoms, such as oppositional defiant disorder or conduct disorder. Mood problems have been described among those with PAE, including symptoms of bipolar disorder and depressive disorders [78]. Therefore, along with ND-PAE, these likely comorbid mood disorders should be carefully considered, as should the new DSM-5 diagnosis of disruptive mood dysregulation disorder [79]. A diagnosis of ND-PAE may represent the most accurate and parsimonious way to explain an alcohol-exposed individual's constellation of symptoms and deficits, but does not preclude the diagnosis of comorbid conditions.

Many individuals meeting criteria for ND-PAE may also meet diagnostic criteria for attention-deficit/hyperactivity disorder (ADHD). For now, this could be considered a co-occurring condition, though the relationship between conditions needs clarification [80, 81]. Of importance, the bulk of ADHD literature does not address whether the individuals studied did (or did not) have PAE, so many ADHD studies are confounded on this issue. This will be important for ADHD researchers to address now and in the future. There is research beginning to distinguish differences in the attentional, neurocognitive, and adaptive function deficits of individuals with ADHD of non-teratogenic cause, compared to those of individuals affected by PAE.



This literature has been reviewed [49], with new studies underway [82].

Using Proposed Diagnostic Criteria for ND-PAE: Diagnostic Codes and Clinical Practice Guidelines

DSM-5 now provides a diagnostic code that can be used to identify ND-PAE. Listed in the main body of DSM-5, in the chapter on Neurodevelopmental Disorders [the first chapter in Section II (Diagnostic Criteria and Codes)], is a category labeled: "Other Specified Neurodevelopmental Disorder" (315.8). [The corresponding ICD-10 code is F88.] The DSM-5 states "this category applies to presentations in which symptoms of a neurodevelopmental disorder that cause impairment in social, occupational or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the neurodevelopmental disorders diagnostic class" (p. 86) [17•]. When applying ND-PAE, the clinician is acknowledging that: (a) PAE is known (or assumed only when the child has classic facial features of FAS); and (b) the full range of symptoms shown by the individual being evaluated are not adequately captured by existing conditions defined as neurodevelopmental disorders. By category, these other existing conditions include the following: intellectual disabilities (or, for young children, global developmental delay); communication disorders; autism spectrum disorder; ADHD; specific learning disorder; and motor disorders. In DSM-5, specifiers are used to communicate the specific reason for rendering a diagnosis of an "Other Specified Neurodevelopmental Disorder." ND-PAE is given as the example specifier for code 315.8. ND-PAE might be used, for example, when PAE is known, a child shows memory deficits, and the child also shows impairment in selfregulation and in two areas of adaptive function (including either social communication or social interaction).

Importantly, a provider choosing to specify ND-PAE as an "Other Specified Neurodevelopmental Disorder" should first take care to consult the chapter on "Conditions for Further Study," in Section III, where the proposed diagnostic criteria are detailed. (*Note*: see pages 798–801 of the complete DSM-5 manual or search the on-line DSM-5 version). The proposed term in the main body of the manual uses the word "neurodevelopmental" in defining ND-PAE. Clinicians should note this is *superceded* by the term given in the actual diagnostic criteria, which is "*neurobehavioral* disorder associated with prenatal alcohol exposure." A provider using the term ND-PAE in clinical practice must consult the complete DSM-5 manual, as the section on "Conditions for Further Study" is, unfortunately, not included in the compact DSM-5 Desk Reference version.

Figure 1 presents clinical guidelines useful when identifying ND-PAE. These will evolve with growing data and clinical experience.

The FASD Diagnostic Specialty Clinic Process

Even with availability of this new DSM-5 category, the gold standard for diagnosing conditions in the category of FASD is still a multidisciplinary or interdisciplinary team assessment. This can occur in either a general child assessment service with specialized knowledge or an FASD diagnostic specialty clinic.

A specialized FASD diagnostic team assessment allows for input of multiple disciplines, such as health care providers (e.g., pediatrics, genetics), psychology, speech/language pathology, occupational therapy, and a family advocate. Team assessment can effectively examine facial dysmorphology and growth impairment, rule out competing medical explanations, and confirm CNS dysfunction with psychometrically sound test results that reveal scores falling below consensus-derived or empirically derived clinical cutoffs. Descriptions of an FASD diagnostic specialty clinic process are available [83]. If a specialized clinic has diagnosed a condition in the category of FASD, and ND-PAE criteria are met, the ND-PAE term is still useful because it can emphasize the importance of FASD-informed care by providers in multiple disciplines.

Intriguingly, a recent study of a large clinical sample, using an FASD diagnostic specialty clinic team assessment, diagnosed 155 of 547 youth with a condition in the category of FASD. The sample was then examined for fit with ND-PAE criteria—one of the first studies to do so. Of those with an FASD, 100 % met proposed ND-PAE diagnostic criteria [5•].

Usefulness of ND-PAE for Treatment Planning and Providing FASD-Informed Care

ND-PAE is viewed as a neurodevelopmental disorder. Identifying ND-PAE potentially provides new understanding of symptoms and the expected treatment course, and modifies case formulation and treatment planning.

Providers can learn more about FASD-informed care to change their own practices. Table 1 provides basic, concise suggestions for providing FASD-informed care. One excellent additional source of information is a Treatment Improvement Protocol ("TIP #58") monograph, titled "Addressing Fetal Alcohol Spectrum Disorders" [18•] and available for free downloading. TIP #58 has a wealth of practical guidance for clinicians and agencies in the areas of substance abuse treatment and mental health.

Also helpful are qualitative data, now available, that shed light on how to use psychological assessment as the initiation of intervention and a way to build capacity for FASD-informed care [84•]. Specialized expert consultation can also



help providers alter their understanding of client behavior and modify treatment strategies when ND-PAE is present, and consultation models are under development now.

Providers can systematically modify their own treatments to provide FASD-informed care. Expert consensus suggests that efficacy of existing interventions can be improved if they are adapted [18•, 85, 86]. Providers can also train in (or refer families to) tailored, efficacious interventions. Several tailored treatments for children affected by PAE and their families have been

found effective in controlled trials [87] and translated into the community [88, 89]. A framework for developing interventions for this clinical population has been proposed [90]. Interesting new treatments are under study now [91–93]. Figure 2 provides a tiered model of psychosocial interventions so far found likely to be helpful when ND-PAE or FASD are identified. These are promising or efficacious interventions that can be included by providers in treatment planning for those with ND-PAE and/or their caregivers.

Fig. 1 Clinical guidelines for use when identifying ND-PAE

Take a supportive, non-judgmental stance toward the issue of prenatal exposures, avoiding stigma or bias (especially toward birth parents or kinship caregivers).

Do a thorough prenatal exposure/risk factor history as part of a larger intake, including looking at birth and social service records, if available.

Obtain all possible evidence of central nervous system dysfunction that can be interpreted within the provider's scope of practice, including archival records if possible.

Carefully compare evidence to proposed ND-PAE diagnostic criteria, using the actual criteria and explanatory text listed on pp. 798-801 of the complete DSM-5 manual (or use the on-line complete version).

If diagnosing ND-PAE, report diagnosis as follows:

Other Specified Neurodevelopmental Disorder: Neurobehavioral
Disorder Associated with Prenatal Alcohol Exposure (ND-PAE).

[Note: Proposed diagnostic criteria are used.]

Thoughtfully diagnose any co-occurring psychiatric conditions, unless ND-PAE alone adequately explains the symptoms.



 Table 1
 Steps in providing FASD-informed care

Key word	Action plan
ASK	Ask questions about prenatal exposure to alcohol and other substances (5)
PREVENT	Act to prevent maternal drinking during pregnancy, now or in the future (5)
DIAGNOSE	If qualified, carry out ND-PAE diagnosis and/or refer for specialized FASD diagnosis (5)
PROTECT	Plan intervention to reduce risk factors (such as adverse childhood experiences) (1, 3, 4) Enhance protective factors specific to the population: Early diagnosis (before age 6 years), appropriate caregiving environment in childhood, not living with caregivers involved in substance abuse, not being victimized, receiving appropriate social services, parental advocacy (1, 3–4)
SUPPORT	Plan intervention to support caregivers (1, 3, 5) Connect caregivers with other families in a similar situation, and/or with FASD parent support and advocacy organizations (1, 3, 5)
USE "REFRAMING"	Educate yourself, caregivers, and other providers about ND-PAE as a neurodevelopmental disorder, and what that means for: Realistic expectations, developmental course, intervention needs, and what defines a successful outcome (1–3, 5)
USE "ACCOMMODATIONS"	Modify the environment—including caregiving, school, job, recreation, and other settings (1–3, 5) Modify treatment: Offer services over a longer period time, expect slower progress, use a more concrete and experiential approach, consider neurodevelopmental deficits when intervening, build on strengths of caregiver and affected individual (2)
USE "BRAINSTORMING"	When appropriate, and if qualified to do so, for caregiver training use positive behavior support and motivational interviewing techiques $(1, 2, 5)$
BUILD SKILLS	Help affected individuals learn to control arousal, build self-regulation, and learn specific skills that are in deficit (e.g., memory, social communication, safety, etc.) (1, 2, 5)
HAVE HOPE	To build hope, take the time to reflect on your own comfort level in dealing with issues related to ND-PAE, and find support as needed (5)

Sources with more detailed information on these ideas: (1) Families Moving Forward Program: http://depts.washington.edu/finffasd/home; (2) Olson and Montague [86]; (3) Olson et al. [9]; (4) Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Seattle, Washington: University of Washington Publication Services; 1996; (5) Substance Abuse and Mental Health Services Administration (SAMHSA) [18•]

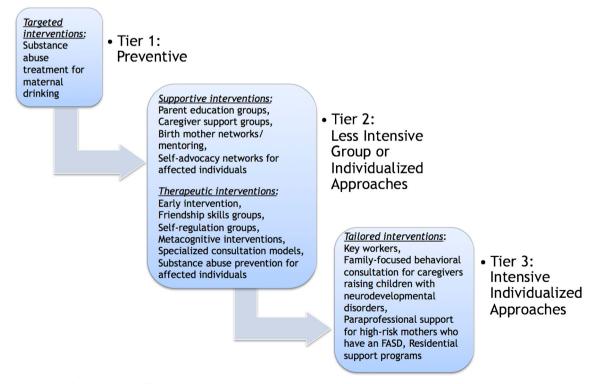


Fig. 2 Tiered model of promising or efficacious psychosocial interventions for those with ND-PAE, or FASD, and their caregivers



Conclusions

As community education about FASD and screening for prenatal exposures becomes the standard of care, there is an urgent need for accessible, practical diagnostic methods that describe the full continuum of debilitating clinical conditions associated with PAE. The proposed diagnostic category of ND-PAE in DSM-5 can help meet this need. As providers become better able to identify ND-PAE, they can then provide FASD-informed care. This means they can adapt services to be more appropriate, access specialized consultation, and learn (or refer to) the growing complement of scientifically validated interventions tailored for those affected by PAE. When needed, they can also refer for specialized FASD diagnostic clinic assessment.

Well-informed use of the proposed diagnosis of ND-PAE can advance recognition of fetal alcohol spectrum disorders. Training on ND-PAE is vital for service providers and students in developmental disabilities, mental health, health care, social service, and related professions. Greater capacity for identification will better reveal prevalence rates, enabling advocacy and public policy efforts to improve the service system. Systematic research is necessary to validate and refine the proposed diagnostic criteria. Fortunately, the DSM has been transformed to function as a "living document" [54•], so the ND-PAE diagnosis can be updated as empirical validation research accrues. Because the ICD and DSM systems co-evolve, what is learned about ND-PAE will benefit ongoing development of equivalent conditions named in ICD-11 [94, 95]. The relationship of the ND-PAE diagnosis to specialized FASD diagnostic guidelines needs empirical study, and these investigations have now started [5•]. Most importantly, though, clinicians need to use and understand ND-PAE as a meaningful aspect of their clients' diagnostic profile—to help in treatment through an improved model of clinical care.

Websites: Sources of Education on FASD, PAE, and ND-PAE, and training on asking questions about PAE:

American Academy of Pediatrics, FASD Toolkit: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx [Accessed May 23, 2015]

Centers for Disease Control and Prevention, FASD Homepage:

http://www.cdc.gov/ncbddd/fasd/training.html [Accessed May 15, 2015]

Centers for Disease Control and Prevention, FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice:

http://www.cdc.gov/ncbddd/fasd/curriculum/index.html [Accessed May 19, 2015]

Minnesota Organization on Fetal Alcohol Syndrome: http://www.mofas.org/ [Accessed April 30, 2015]

National Organization on Fetal Alcohol Syndrome: http://www.nofas.org/ [Accessed May 20, 2015]

National Center for Biotechnology Information: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2139915/ [Accessed May 26, 2015]

Substance Abuse and Mental Health Services Administration, FASD Center for Excellence:

http://fasdcenter.samhsa.gov/ [Accessed May 23, 2015]

Compliance with Ethics Guidelines

Conflict of Interest Heather Carmichael Olson reports grants from Centers for Disease Control and Prevention, other from Bentham Science Publishers, other from National Institute on Alcohol Abuse and Alcoholism other from National Institute on Alcohol Abuse and Alcoholism.

Human and Animal Rights and Informed Consent Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in studies by the author found in this article.

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