Alcohol-Related Neurobehavioral Disabilities: Need for Further Definition and Common Terminology

H. Eugene Hoyme, MD,^{a,b} Claire D. Coles, PhD^c

The adverse effects of alcohol on the developing human comprise a continuum of disabilities termed fetal alcohol spectrum disorders (FASD). In the current issue of *Pediatrics*, Hagan et al¹ discuss the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), of the American Psychiatric Association's suggestion for inclusion of a new mental health diagnosis as part of this continuum; that is, neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE).² The present commentary addresses the definition of ND-PAE, how it intersects with the existing diagnostic categories of FASD (fetal alcohol syndrome [FAS], partial fetal alcohol syndrome [PFAS], alcohol-related birth defects, and alcohol-related neurodevelopmental disorder [ARND]),³ and the need for ongoing research and development of common terminology for FASD.

ND-PAE is listed in DSM-5 as an experimental "Condition for Further Study," and thus currently cannot be diagnosed. However, the effects of prenatal alcohol exposure are also included under "Other Specified Neurodevelopmental Disorder" (315.8) with a slightly different definition.² In both cases, this category is intended for use by mental health professionals, including psychiatrists, psychologists, social workers, nurses, and counselors who cannot make a diagnosis using medical codes.⁴ DSM-5 codes trigger payment for behavioral health services and can help direct referral of affected children for necessary

interventions and treatments, making it important for pediatricians to become familiar with the term. In addition, conceptualizing the behavior of alcohol-affected children in these terms can help pediatricians screen for and monitor FASD when it presents in their practices. Better identification and monitoring of affected children will benefit patients, allow evaluation of the reliability and validity of ND-PAE, and permit exploration of the utility of applying the diagnosis to all exposed individuals.

At present, it is premature to assume that ND-PAE, as defined in the accompanying article,¹ applies to all of the behavioral and mental health effects observed in FASD, with and without the classic structural features associated with prenatal alcohol exposure. We assert that ARND should continue to be a recognized diagnostic category, at least for the time being. It is a well-validated entity that can be assigned in a multidisciplinary medical diagnostic setting.⁵ In addition, since the structural findings in FAS and PFAS are more specific and predictive of FASD than the neurobehavioral phenotype, it has been suggested that the neurobehavioral diagnostic criteria in children with the classic dysmorphic features associated with prenatal alcohol exposure (FAS/PFAS) need not be identical to those in affected children without dysmorphia (ARND), who may not have all the characteristics of ND-PAE.⁵ As proposed, the ND-PAE criteria require a greater number of neurobehavioral

^aSanford Research and Department of Pediatrics, Sanford School of Medicine, University of South Dakota, Sioux Falls, South Dakota; ^bCenter for Applied Genetics and Genomic Medicine and Department of Pediatrics, University of Arizona College of Medicine, Tucson, Arizona; and ^cDepartment of Psychiatry and Behavioral Sciences and Department of Pediatrics, Emory University School of Medicine, Atlanta, Georgia

DOI: 10.1542/peds.2016-1999

Accepted for publication Jul 22, 2016

Address correspondence to H. Eugene Hoyme, MD, Genetics and Genomic Medicine, Sanford Health, PO Box 5039, Sioux Falls, SD 57117-5039. E-mail: gene.hoyme@sanfordhealth.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2016 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by the National Institute on Alcohol Abuse and Alcoholism grants R01 AA11685, R01/U01 AA015134, and U01 AA019879-01/NIH-NIAAA (Collaboration on FASD Prevalence) and by the Oxnard Foundation. Funded by the National Institutes of Health (NIH).

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2015-1553.

To cite: Hoyme HE and Coles CD. Alcohol-Related Neurobehavioral Disabilities: Need for Further Definition and Common Terminology. *Pediatrics*. 2016;138(4):e20161999

characteristics than in ARND.¹ Further study of NDPAE, particularly if it is performed in a sizable research cohort, may eventually lead to endorsement by major health professional organizations, including the American Academy of Pediatrics.

Hagan et al¹ suggest that ND-PAE can be assigned as a comorbid diagnosis accompanying a diagnosis of FAS or PFAS. By definition (in all diagnostic systems for FASD), specific neurobehavioral/neurodevelopmental criteria must be met to assign a diagnosis of FAS or PFAS.^{5–10} Thus, dual assignment of a diagnosis of ND-PAE and FAS or PFAS may seem redundant to the physician. However, because many mental health practitioners cannot assign medical diagnoses, such as FAS, the DSM-5 code permits billing for services that would otherwise not be reimbursed.

The authors of this commentary are cognizant of the resource limitations that face individuals seeking an FASD diagnosis. However, because the alcohol-affected child often has both physical and developmental problems, the assignment of an FASD diagnosis is best accomplished by a multidisciplinary team comprising members with complementary skills, experience, and qualifications.^{5,6} The approach outlined by Hagan et al makes such a multidisciplinary assessment optional. We suggest that every child who is evaluated for FASD must have expert assessment of growth and dysmorphology in addition to skilled neurobehavioral/neurodevelopmental evaluation. A multidisciplinary team approach is a time-honored, well-proven method of providing accurate, up-to-date, and comprehensive diagnosis and management for children with disabilities and chronic/complex conditions.¹¹ Rather than excluding the primary pediatrician from the care of the affected child, the multidisciplinary approach requires that the team work closely with

the pediatrician to provide an all-inclusive medical home. Some argue that the paucity of pediatricians trained in dysmorphology makes an FASD multidisciplinary team impractical. Instead of designing a system that may provide an incomplete evaluation of potentially affected children, training of pediatric residents and general pediatricians in this area should be a priority. In fact, Jones et al¹² reported on the accuracy of pediatricians in recognizing FAS after a relatively short training session.

Although the original Institute of Medicine framework continues to provide the most comprehensive description of the continuum of disabilities in FASD, it was never intended to be the final word on this issue,³ and after 2 decades of research and hundreds of publications, the medical literature still demonstrates a lack of uniformity in diagnostic approach and associated terminology. Given the high prevalence of this group of disorders and their preventable nature, it behooves investigators in the field to search for common ground. A further, comprehensive investigation of the ND-PAE construct is a step in the right direction.

ACKNOWLEDGMENTS

The authors are grateful for the input and review of this commentary by our colleagues: Wendy O. Kalberg, MA, LED, from the Center on Alcoholism, Substance Abuse and Addictions of the University of New Mexico; Prachi E. Shah, MD, from the Department of Pediatrics and Communicable Diseases of the University of Michigan Medical School; and Amy J. Elliott, PhD, from Sanford Research and the Department of Pediatrics, Sanford School of Medicine of the University of South Dakota.

ABBREVIATIONS

ARND: alcohol-related neurodevelopmental disorder
DSM-5: *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*
FAS: fetal alcohol syndrome
FASD: fetal alcohol spectrum disorders
IOM: Institute of Medicine
ND-PAE: neurobehavioral disorder associated with prenatal alcohol exposure
PFAS: partial fetal alcohol syndrome

REFERENCES

1. Hagan JF, Balachova T, Bertrand J, et al. Neurobehavioral disorder associated with prenatal alcohol exposure. *Pediatrics*. 2016;138(4):e20151553
2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington, DC: American Psychiatric Association; 2013:86, 798–801
3. Stratton K, Howe C, Battaglia F, eds. *Institute of Medicine. Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington, DC: National Academies Press; 1996
4. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. Available at: www.psychiatry.org/psychiatrists/practice/dsm. Accessed June 13, 2016
5. Hoyme HE, Kalberg WO, Elliott AJ, et al. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*. 2016;138(2):e20154256
6. Hoyme HE, May PA, Kalberg WO, et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 Institute of Medicine criteria. *Pediatrics*. 2005;115(1):39–47
7. Astley SJ, Clarren SK. Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit

- diagnostic code. *Alcohol Alcohol*. 2000;35(4):400–410
8. Astley SJ. FAS Diagnostic and Prevention Network. Available at: <https://depts.washington.edu/fasdpn/htmls/4-digit-code.htm>. Accessed June 13, 2016
 9. Chudley AE, Conry J, Cook JL, Looock C, Rosales T, LeBlanc N; Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ*. 2005;172(suppl 5):S1–S21
 10. Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ*. 2015;188(3):191–197
 11. Grosse SD, Schechter MS, Kulkarni R, Lloyd-Puryear MA, Strickland B, Trevathan E. Models of comprehensive multidisciplinary care for individuals in the United States with genetic disorders. *Pediatrics*. 2009;123(1):407–412
 12. Jones KL, Robinson LK, Bakhireva LN, et al. Accuracy of the diagnosis of physical features of fetal alcohol syndrome by pediatricians after specialized training. *Pediatrics*. 2006;118(6). Available at: www.pediatrics.org/cgi/content/full/118/6/e1734