Statement posted by: Dr. Julie Kable (*FASDSG Secretary*) Marcus Autism Center Department of Pediatrics Emory University School of Medicine

This comment is to request that a behaviorally defined diagnosis of Alcohol Related Neurodevelopmental Disorder (ARND), which is the most common outcome of prenatal alcohol exposure, be considered for inclusion in the DSM-V. The current situation is that the DSM-IV omits conditions related to alcohol exposure entirely, leaving clinicians with only a single ICD-10 code that describes Fetal Alcohol Syndrome (dysmorphic, 086.0). One other code (P04.3) only allows for effects in early infancy. These codes make no allowances for the overwhelming majority of affected individuals who do not have all or any of the physical manifestations associated with prenatal alcohol exposure. Additionally, most psychologists and psychiatrists do not use ICD-10 codes in practice. The omission of conditions related to prenatal alcohol exposure is not responsive to an extensive body of well-designed research, diagnostic practice and clinical experience across multiple professional disciplines that have developed over the past 35 years describing a spectrum of alcohol related effects. I believe it is responsible, appropriate, and ethically indicated to include ARND in the DSM-V.

Overwhelming evidence, including longitudinal human research and clinical study, supported by research with animal models, has prompted increased attention to the role of prenatal alcohol exposure in the occurrence of a wide range of disorders known as Fetal Alcohol Spectrum Disorders (FASDs). The term "fetal alcohol spectrum disorders" was accepted in 2004 by consensus by governmental, research and advocacy organizations (http://www.nofas.org/advocate/terminology.aspx) and is considered a global public health concern. Fetal Alcohol Syndrome (FAS) is one of the most identifiable conditions on the fetal alcohol spectrum resulting from in utero alcohol exposure. But an extensive body of literature, including neuroimaging and neuropsychological studies from multiple research laboratories, has documented significant and consistent neurocognitive and behavioral difficulties among individuals with prenatal alcohol exposure who do not meet full criteria for FAS.

Recent prevalence rates of those with conditions collectively known as FASDs are estimated as high as 1 in 100 in the United States. This prevalence rate is higher than that found for individuals with autism spectrum disorders, another important set of neurodevelopmental

disabilities which is also the focus of active research investigation. The National Institutes of Health have recently issued requests for proposals to carefully survey the prevalence of FASDs through active screening mechanisms in the United States, and there are many countries that already have screening and diagnostic methods in place to promote reliable identification of this recognizable and debilitating set of conditions (e.g. Canada).

Further, individuals with FASDs are at increased risk for psychiatric illness and in need of mental health treatment, estimated at over 90% in this population, in the school years and into adulthood. As children, these individuals are often characterized as having Attention Deficit/Hyperactivity Disorder, Oppositional Defiant Disorder, Mood Disorders, Disruptive Behavior Disorder, or even Conduct Disorder. While they may meet criteria for these disorders, these labels do not adequately describe their symptoms or prognosis, nor do they suggest appropriate treatments. Moreover, individuals with prenatal exposure to alcohol have been found to be impacted throughout their lives showing an increased risk of suicide, substance abuse disorders, as well as other severe psychiatric disorders.

The most common manifestation of the impact of prenatal alcohol exposure is seen among individuals described by the Institute of Medicine and throughout the research literature as having alcohol related neurodevelopmental disorder (ARND). These individuals have a behavioral phenotype that is true to the wide-ranging and individually variable physiological impact of alcohol exposure in utero. Individuals with ARND show clinically significant problems in multiple domains. These domains can include communication, abstract reasoning, memory, learning, executive function, adaptive behavior and attention, to name a few. Unlike earlier research, recent findings show that a majority of individuals with prenatal alcohol exposure do not have mental retardation; rather their problems are seen more in their inability to function adaptively in their environments.

Unfortunately, most psychiatrists and mental health providers are not trained to inquire about the use of alcohol during pregnancy, nor are they adequately trained to make a diagnosis of this neurodevelopmental disability. In the past, mental health professionals similarly were not trained to identify other conditions, such as autism spectrum disorders, which was remediated by recognizing these conditions within the diagnostic nomenclature even when there was still controversy and active research investigation. The lack of awareness of alcohol as a neurobehavioral teratogen, despite clear experimental evidence, results in many failed treatment attempts and unnecessary hardship for patients and their families. Extensive clinical experience shows that individuals with ARND may not respond as expected to well established medication regimens and to many forms of psychotherapy, particularly if such interventions are not tailored in accordance with their profile of neurodevelopmental impairments. For this reason, it is important to know that an individual has been exposed to alcohol prenatally before developing a treatment plan. Accurate description and training of mental health professionals on characteristic symptomotology is crucial.

As a member of a national scientific working group charged by the Federal Government with defining the behavioral phenotype associated with ARND, I respectfully submit the following proposed diagnostic criteria. This definition is a work in progress and members of our committee would be glad to work with members of the DSM-V diagnostic work groups to further refine these criteria making them suitable for inclusion in the DSM-V. I believe that inclusion of ARND in the DSM-V will increase awareness of this debilitating neurodevelopmental disorder, result in a more accurate diagnosis, prompt more appropriate treatment plans, and lead to better mental health outcomes. Omitting ARND would mean that the DSM-V would not represent the state of the art of research and clinical practice.

Following are the suggested diagnostic criteria for Alcohol Related Neurodevelopmental Disorder (ARND).

A. A confirmed history of alcohol exposure as evidenced by 3 or more standard drinks per drinking occasion (on average) or more than 7 standard drinks per week (on average) prior to pregnancy recognition and/or following pregnancy recognition. A standard drink is defined as .60 oz of absolute alcohol (e.g. one 12 oz beer, one 5 oz glass of wine, one drink with 11/2 oz distilled spirits, one 12 oz wine cooler). If alcohol exposure levels are not available in the case of foster or adopted children or unavailable birth mother report, evidence of significant exposure should come from; (1) a reliable source (spouse, partner, relative, friend) who observed the birth mother drinking alcohol heavily or saw her intoxicated during pregnancy; or (2) from the birth mother's medical, police, substance abuse treatment or court records, or the patient's medical, court, or child welfare records, indicating alcohol use or other social, legal or medical problems related to maternal drinking during pregnancy.

B. Evidence of central nervous system neurodevelopmental abnormalities including neurological signs (e.g., seizure disorder) not resulting from a postnatal insult or fever, evidence of structural brain abnormalities such as microcephaly or evidence observable through neuroimaging (e.g., clinically meaningful abnormalities of the corpus callosum, basal ganglia,

cerebellum, etc.), or global cognitive or intellectual deficits representing multiple domains of deficit (or substantial developmental delays in younger children) with performance below the 3rd percentile (i.e., - 2 standard deviations below the mean on standardized testing).

Or

C. Suspected central nervous system dysfunction, without reference to IQ, as manifested by performance below age expectations as measured by standardized neuropsychological, developmental, or clinical tests (at least - 1 standard deviation below the mean or above the cut point for clinical caseness) or by clinical report or observation of the patient in 3 or more of the following domains:

- 1. Executive function (e.g., poor planning, poor judgment, deficits in cognitive or behavioral flexibility, poor organizational skills, needs adult supervision to perform complex multistep tasks)
- 2. Learning (e.g., poor academic achievement, difficulty encoding material, requiring or receiving special education services)
- 3. Memory (e.g., problems in short term or working memory, does not remember something learned recently, requires frequent reminders)
- 4. Language or communication (e.g., poor receptive or expressive language skills, poor pragmatics, or poor performance on measures of narrative ability on other measures of integrative language abilities)
- 5. Visual spatial skills (e.g., difficulty with basic or complex drawing tasks, problems discriminating left from right, gets lost easily)
- 6. Fine or gross motor skills (e.g., delays in achieving fine or gross motor developmental milestones, poor balance or coordination, poor writing skills)
- 7. Adaptive function (difficulty in tasks of daily living such as dressing, toileting, feeding, safety, maintaining employment, managing finances, independent living)
- 8. Social skills (e.g., gullibility, naivetÇ, socially immature, younger friends, no friends, socially indiscriminate, difficulty reading social cues, difficulty understanding social consequences)
- 9. Abstract reasoning (e.g., trouble understanding jokes, analogies, or idioms, problems in deductive reasoning)
- 10. Activity level (e.g., difficulty remaining seated at school, always on the go, fidgety, hyperactive)
- 11. Attention (e.g., difficulty sustaining attention during tasks, easily distracted)

12. Impulse control or response disinhibition (e.g., perseverative behavior, difficulty withholding responses, difficulty delaying gratification, emotional lability)

Assessment of very young children may be difficult to evaluate according to domains, or problems may not yet be clearly manifest. For these young children, individually-administered developmental assessments can be used to provide evidence of impairment. But given the lack of sensitivity of early developmental testing, precursor or early-developing skills in domains such as behavior regulation, attention regulation, sensory sensitivities, sleep abnormalities, delayed language, play, or social skills should be considered.

D. The disturbances in Criteria B and/or C significantly interfere with academic or occupational achievement, and activities of daily living (including those of a very young child) that require the use of these skills.

E. If a vision/hearing impairment is present, the difficulties (noted in C above) cannot be explained by sensory impairment alone.

F. The pattern of test results cannot be explained solely by the impact of familial background, genetic or metabolic factors, or postnatal environment.

G. The condition existed prior to 18 years of age.

H. If the individual meets criteria for a specific learning disorder, behavioral dysregulation disorder (including clinically significant internalizing or externalizing behavior problems), or psychiatric disorder, these disorders should also be coded as co- morbidities.

*If the individual also presents with growth retardation and/or abnormal facial features (short palpebral fissures, thin vermillion border, flat philtrum), they should be further evaluated for the presence of fetal alcohol syndrome (FAS).

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