Understanding the Relationship between Prenatal Substance Exposure and Mental and Behavior Health Challenges in Foster Youth

SUMMARY:

1. Mental and behavioral health challenges were found to be extremely similar between substance exposed and non-substance exposed foster youth in a study of 540 subjects, indicating that substance exposure is not a major predictor of these challenges.

2. Factors such as early neglect from insufficient caregiving leading to inadequate early cognitive development and emotion regulation may be stronger contributors to mental and behavioral health challenges in foster youth compared to prenatal substance exposure.

3. The study highlighted that developmental delays, behavioral and emotional disorders, and, adolescent/adult onset disorders were prevalent among both substance-exposed and non-substance exposed youth in family foster care and group homes, with slightly higher percentages in group homes for some disorders.

4. Family-based interventions could potentially help mitigate the effects of early neglect and insufficient caregiving on mental and behavioral health challenges in foster youth.

5. The study also pointed out that the exposed youths were typically placed in out-of-home care at a younger age than the controls, with differences in the timing and frequency of placements between the two groups. Additionally, some exposed youths had lower birth weights, and a portion had received diagnoses related to Fetal Alcohol Spectrum Disorder (FASD) and Neonatal Abstinence Syndrome (NAS).

Understanding the Relationship between Prenatal Substance Exposure and Mental and Behavior Health Challenges in Foster Youth

(according to one study, published in 2023 , with a total sample size of 540 foster youth subjects)

According to a study published in 2023 of 540 foster youth, mental and behavioral health challenges were EXTREMELY similar between substance-exposed and non-substance exposed foster youth. According to this study, substance exposure is not a major predictor of mental and behavioral health challenges. What then, might be the strongest contributors to mental and behavioral health challenges for foster youth? Could these include early neglect from insufficient caregiving leading to lack of sufficient early cognitive development and early development of sufficient emotion regulation? What family-based interventions are there to potentially mitigate these effects?

Prevalence of mental and behavioral disorders in relation to the type of out-of-home care among youth with and without substance

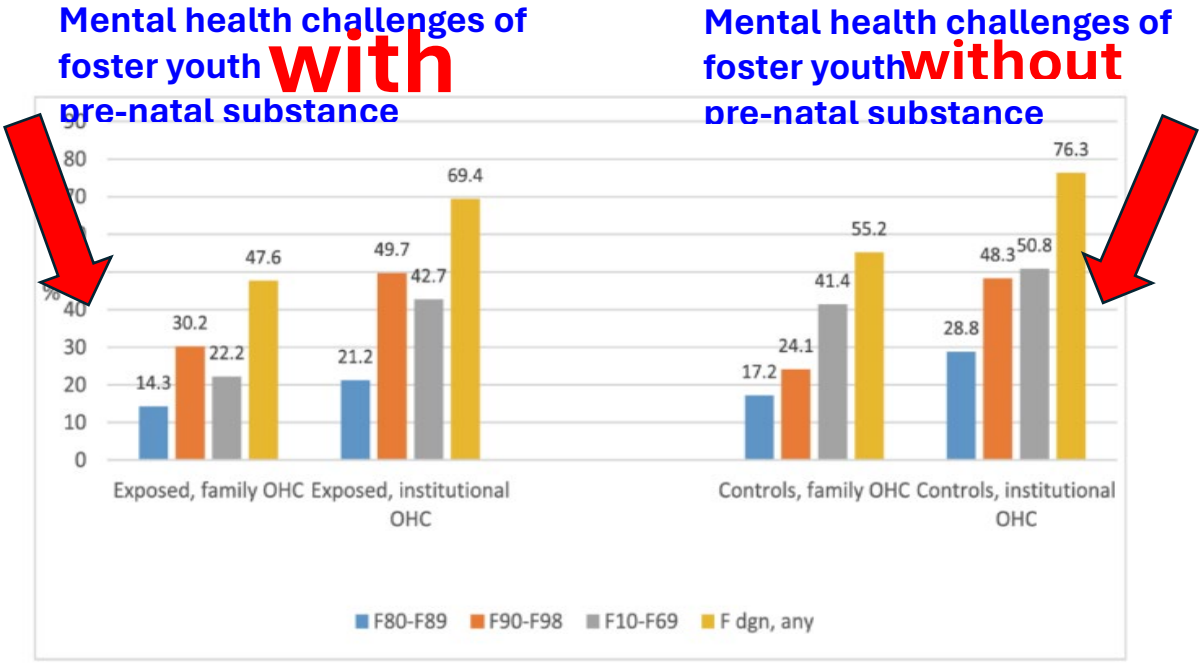


Fig. 1a. Prevalence of mental and behavioral disorders in relation to the type of out-of-home care among exposed and control youths (%, exposed n = 393, controls, n = 147). Difference between family-type OHC only/family + institutional OHC: Exposed: F80-F89, p = 0.209, F90-F98, p = 0.004, F10-F69, p = 0.002, F-dgn, any, p < 0.001. Controls: F80-F89, p = 0.206, F90-F98, p = 0.019, F10-F69, p = 0.361, F-dgn, any, p = 0.023.

KOPONEN, A. *et al.* Out-of-home care and diagnosed mental and behavioral disorders among youth with and without prenatal substance exposure-A longitudinal register-based cohort study. **CHILDREN AND YOUTH SERVICES REVIEW**, *[s. l.]*, v. 143, 2022. DOI 10.1016/j.childyouth.2022.106683.

ICD F80-F89: Disorders of psychological development (F80- F89) include disorders of speech, language, scholastic skills, and motor functions.

	% of non-Substance Exposed youth in family foster care with disorders	% of Non-substance exposed youth in group homes with disorders
F10-F89: developmental delays	17.2%	28.8%
F90-F98: Behavioral and emotional disorders	24.1%	48.3%
F10-F69: adolescent and adult onset disorders	41.4%	50.8%
F dsn: any disorder	69.4%	76.3%

	% of Substance Exposed youth in family foster care with disorders	% of Non-substance exposed youth in family foster care with disorders
F10-F89: developmental delays	14.3%	17.2%
F90-F98: Behavioral and emotional disorders	30.2%	24.1%
F10-F69: adolescent and adult onset disorders	22.2%	41.4%
F dsn: any disorder	47.6%	55.2%

	% of Substance Exposed youth in group homes with disorders	% of Non-substance exposed youth in group homes with disorders
F10-F89: developmental delays	21.2%	17.2%
F90-F98: Behavioral and emotional disorders	49.7%	48.3%
F10-F69: adolescent and adult onset disorders	42.7%	50.8%
F dsn: any disorder	69.4%	76.3%

	% of Substance Exposed youth in family foster care with disorders	% of substance exposed youth in group homes with disorders
F10-F89: developmental delays	14.3%	21.2%
F90-F98: Behavioral and emotional disorders	30.2%	49.7%
F10-F69: adolescent and adult onset disorders	22.2%	42.7%
F dsn: any disorder	47.6%	69.4%

Other questions to look at:

problems	% of **Substance Exposed** youth in **any type of care with 1-3 placements** with disorders	% of **Non-substance exposed** youth in **any type of care** with **1-3 placements** with disorders
problems	% of **Substance Exposed** youth in **any type of care with 4-9 placements** with disorders	% of **Non-substance exposed** youth in **any type of care** with **4-9 placements** with disorders

problems	% of **Substance Exposed** youth in **foster family care with 1-3 placements** with disorders	% of **Non-substance exposed** youth in **foster family care** with **1-3 placements** with disorders
problems	% of **Substance Exposed** youth in **foster family care with 4-9 placements** with disorders	% of **Non-substance exposed** youth in **foster family care** with **4-9 placements** with disorders

Potential study problem with trying to generalize this study to a US population: Seemingly no cultural or ethnic diversity?

Background factors and mental and behavioral disorders among exposed and control youths (%, n).
Exposed, n = 393 % (n) Controls, n = 147 % (n) p-value
Sociodemographic background and maternal risks
Sex 0.403 Male 50.4 (198) 54.4 (80) Female 49.6 (195) 45.6 (67)
Age at the end of follow-up 2016 0.066 15–17 years 40.2 (158) 49.0 (72) 18–24 years 59.8 (235) 51.0 (75)

Native language <0.001 Finnish or Swedish exposed: 99.7 (391) controls: 91.8 (135);

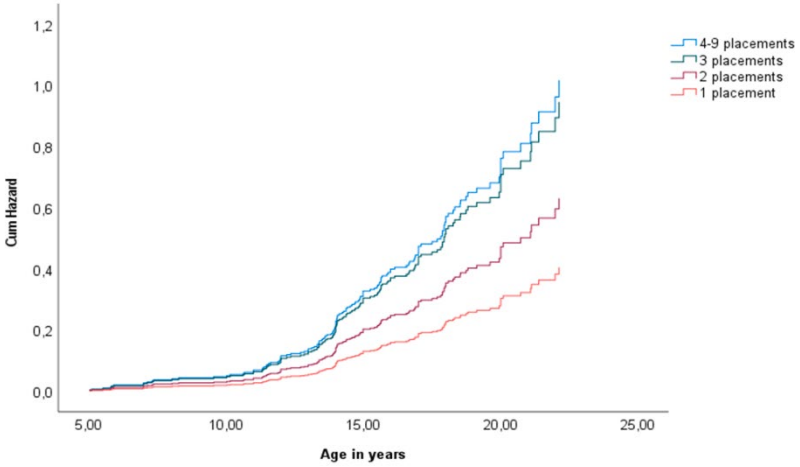
Other (child of immigrant parents) exposed:0.3 (1); controls: 8.2 (12)

Additional Information about this study

The exposed youths were placed at a younger age than the controls.
Half of the exposed were placed for the first time before the age of three and almost one-fifth before the age of six months. The corresponding figures among the controls were 15 % and 3 %. The first placement among the controls was typically at school age or teenage. Almost half of the controls had only one placement while less than one-fifth of the exposed had one placement and half had three or more placements. Almost half of the exposed had been in OHC for at least 50 % of their lifetime (controls 10.2 %). The exposed were most typically placed in a children's home or a foster family, and the controls in a children's home. Only a minority had been in a family-type care all of their time in OHC (exposed 16.0 %, controls 19.8 %). This minority had the most stable OHC history with the smallest number of placements. (Table 2.).

The exposed offspring had slightly lower birth weight, but the difference did not reach statistical significance. Among the exposed, 10.2 % had received a diagnosis under a FASD continuum and 9.7 % had a Neonatal Abstinence Syndrome (NAS) diagnosis. (Table 1.) No significant differences between the exposed and the controls were found in gestational age and 1-minute Apgar-scores (data not shown).

Number of Placements and Severity of Disorders



Recognizing Alcohol-Related Neurodevelopmental Disorder (ARND) in Primary Health Care of Children

Consensus Statement. A Conference Organized by the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD)

Definition of ARND & FASD:

- Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term for a range of disabilities resulting from prenatal alcohol exposure, including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), ARND, and alcohol-related birth defects (ARBD).
- ARND refers to a complex range of disabilities in neurodevelopment, behavior, adaptive skills, and self-regulation in the presence of confirmed prenatal alcohol exposure.

Diagnosis of ARND

- ARND can be diagnosed based on evidence of central nervous system developmental abnormalities and a complex pattern of behavior and cognitive abnormalities.
- Differentiating ARND from other disorders can be challenging due to limited studies distinguishing ARND from other complex neurodevelopmental disorders.

Evidence of ARND Diagnosis:

- An ARND diagnosis requires confirmed significant prenatal alcohol exposure, which can be determined through various sources like maternal self-report or medical records.
- There is no known safe threshold for prenatal alcohol exposure, making it impossible to define a safe limit of alcohol consumption during pregnancy.

Screening Criteria:

- Regular screening for alcohol use in women of childbearing age is recommended to protect maternal and child health.
- Primary care clinicians should be alert for signs and symptoms of ARND in children, conducting comprehensive evaluations for those at risk

Treatment Needs:

- Treatment for ARND should be multimodal, specific to individual strengths and weaknesses, and drawn from evidence-based practices.
- Interventions may target academic impairments, social functioning, self-regulation, and adaptive skills, with a need for further research on medication effectiveness and educational interventions.

CONSENSUS STATEMENT

Recognizing Alcohol-Related Neurodevelopmental Disorder (ARND) in Primary Health Care of Children

October 31–November 2, 2011 ▪ Rockville, MD 20852

Consensus Statement on

Recognizing Alcohol-Related Neurodevelopmental Disorder (ARND) in Primary Health Care of Children

A Conference Organized by the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD)

Oct. 31–Nov. 2, 2011, Rockville, MD

Introduction

The nondiagnostic umbrella term "fetal alcohol spectrum disorders (FASD)" is now used to characterize the full range of damage from prenatal alcohol exposure, varying from mild to severe and encompassing a broad array of physical defects and cognitive, behavioral, emotional, and adaptive functioning deficits. FASD includes diagnoses such as fetal alcohol syndrome (FAS), partial FAS (pFAS), ARND, and alcohol-related birth defects (ARBD), which are congenital anomalies including malformations and dysplasias of the cardiac, skeletal, renal, ocular, auditory, and other systems.

The negative effects of prenatal alcohol exposure on the developing brain and the resulting neurological and/or cognitive, behavioral, emotional, and adaptive functioning deficits are seen in individuals with FAS, pFAS, and ARND. Significant alcohol exposure early in prenatal development often results in growth retardation and facial anomalies. These physical characteristics have been useful tools for diagnosing FAS and pFAS. Identifying persons who do not have the physical characteristics of FAS but do have neurodevelopmental disorders induced by prenatal alcohol exposure has proven to be much more challenging, with broad implications. Current prevalence estimates for FAS range from 0.5 to 7 cases per 1,000 live births in the United States, and the prevalence of FAS and ARND combined is thought to be three times that of FAS alone.

In 2004, the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention and the National Task Force on FAS and Fetal Alcohol Effect issued *Guidelines for Referral and Diagnosis of FAS*. Evidence for recommending screening and referral for diagnosis of ARND was considered insufficient at that time. In the past 7 years, a large body of research evidence has been published on further characterization and differentiation of the cognitive, behavioral, emotional, and adaptive functioning deficits

associated with prenatal alcohol exposure. Based on this evidence and identification of the principal issues with researchers and clinicians, ICCFASD determined that the time had come to reassess whether sufficient evidence now existed to recommend screening and/or referral for diagnosis of ARND in primary health care of children. ICCFASD then proceeded to convene a conference during which a multidisciplinary panel would respond to the principal issues, with the objective of arriving at a statement that would advance an understanding of the issue and that would be useful to health care professionals. This document summarizes the outcome of the conference.

Process

In late 2011, ICCFASD assembled a broad-based, independent panel of knowledgeable and unbiased critical thinkers to hear and evaluate evidence presented by experts in the field of FASD. The goal of the conference was to arrive at recommendations and future directions on whether to encourage screening and diagnosis (or referral for diagnosis) of ARND in primary health care of children.

The consensus statement that follows was prepared by the panel, which included health care professionals, biomedical researchers, academics, educators, and child advocate/policy/legal representatives. It is based on (1) relevant published studies assembled by the scientific committee of the conference, (2) presentations of data from the peer-reviewed scientific literature by experts working in areas relevant to the conference questions, (3) questions and comments from conference attendees during open discussion periods, and (4) closed deliberations by the panel. This statement is an independent report of the panel and is not a policy statement of ICCFASD or the National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health; the Centers for Disease Control and Prevention; or the American Academy of Pediatrics, which cosponsored the conference.

Conference Questions

The panel used the evidence presented to them by the experts in the field to develop answers, in the form of a consensus statement, to the following questions:

1. What is ARND; how can it be diagnosed (classical, current diagnostic schemes, in practice today)?
    Part A: Evidence of Central Nervous System Developmental Abnormalities
    Part B: Evidence of a Complex Pattern of Behavior and Cognitive Abnormalities
2. Can ARND be differentiated from other disorders?
3. What prenatal alcohol exposure evidence is necessary for an ARND diagnosis?
4. What signs/symptoms will be useful as screening criteria?
5. What are the treatment needs for those diagnosed with ARND?

Preamble

Children, adults, and families who live with disabilities related to prenatal alcohol exposure (PAE) face extraordinary challenges daily. The work of clinicians and researchers who have worked to understand and improve outcomes on their behalf must be commended. Together, this community has pioneered medical, educational, social, and scientific initiatives, all in pursuit of improving the quality of life for those affected and their families and of reducing the public health burden resulting from PAE.

PAE can cause significant neurodevelopmental and behavioral disorders as well as adaptive and self-regulatory impairments that can have lifelong consequences. Early diagnosis and intervention may help to reduce the long-term challenges potentially facing individuals with PAE. Therefore, primary health care clinicians serving children[1] should be alert to evidence of any maternal use of alcohol during pregnancy in order to provide timely evaluations and appropriate interventions for affected children and help prevent PAE during future pregnancies.

Question 1: What is ARND; how can it be diagnosed (classical, current diagnostic schemes, in practice today)?

Alcohol-related neurodevelopmental disorder (ARND) refers to a complex range of disabilities in neurodevelopment and behavior, adaptive skills, and self-regulation in the presence of confirmed PAE. ARND is one of the fetal alcohol spectrum disorders that also include fetal alcohol syndrome (FAS), which is additionally characterized by distinct facial features and growth retardation.

The term ARND was used in a 1996 report developed under the auspices of the Institute of Medicine (IOM)[2] to recognize the existence of neurodevelopmental disorders associated with confirmed PAE. Specifically, individuals with ARND do not present with the FAS facial phenotype (reduced palpebral fissure length, smooth philtrum, and thin upper vermillion border), but may present with structural and/or functional central nervous system (CNS) abnormalities, and may or may not present with growth deficiencies or decreased cranial size at birth. Acknowledging some degree of uncertainty that PAE caused the presenting adverse effects in any particular individual, the 1996 IOM report on FAS defined ARND as CNS neurodevelopmental abnormality evidenced by decreased cranial size at birth, or structural brain

[1] Primary health care clinicians for children include pediatricians, pediatric nurse practitioners, family medicine physicians, family nurse practitioners, pediatric and family physician assistants, and certain nurses in public health clinics or school-based health clinics.

[2] Stratton K, Howe C, Battaglia F. (Eds.) *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Washington, DC: National Academies Press, 1996. Available online at: *http://www.nap.edu/openbook.php?isbn=0309052920.*

abnormalities, or neurological hard or soft signs in the presence of a pattern of confirmed excessive maternal prenatal alcohol use. Alternatively, ARND could be defined by evidence of a complex pattern of behavioral and cognitive abnormalities that are inconsistent with developmental level and cannot otherwise be explained by the genetic contribution of the biological parents, nor by impairments in brain maturation conferred by adverse environmental factors. Alternative descriptors have emerged, including "neurodevelopmental disorder/alcohol exposed" and "static encephalopathy/alcohol exposed."[3] In the ensuing years, animal research and human studies have helped families, clinicians, and researchers develop a deeper understanding of the relationship between PAE and neurodevelopmental manifestations subsequently evident in children, adolescents, and adults.

Part A: Evidence of CNS Developmental Abnormalities

The brain is susceptible to the neurotoxic effects of alcohol at all stages of gestation. Based on extensive, mutually reinforcing animal and clinical research, there appear to be patterns of significant structural and functional changes in the CNS attributable to PAE. Basic research suggests that numerous processes of neuronal development and functioning can be affected by PAE. Animal studies demonstrate that the timing, dose, and frequency of PAE differentially harm specific neuronal structures and brain circuits. Brain imaging and cognitive and behavioral studies have substantiated similar structural and functional alterations in humans.

Part B: Evidence of a Complex Pattern of Behavior and Cognitive Abnormalities

There is clear and compelling evidence from animal studies that PAE negatively affects behavior, cognition, motor function, self-regulation and adaptive function, executive function, activity, and mood in a complex way. Children with PAE frequently exhibit behavioral and emotional problems such as inattention, hyperactivity, anxiety, and mood dysregulation. These problems may emerge early in life and continue to significantly impair an individual's functioning in numerous domains throughout the lifespan. Identified problems may be primary to PAE, be primary to a comorbid condition, or result from the contribution of and interaction among a number of factors, including interactions with the environment. Research with children suggests that PAE can be associated with general cognitive impairments and specific impairments in the following areas: information processing, attention, executive function, language, memory/learning, social cognition, number processing, and sensorimotor function. One or more behavioral and cognitive phenotypes specific to PAE have been elusive. Identification of specific phenotypes is confounded by variability of exposure (dose, duration, and timing) and potential interactions among other factors, which may include qualities of the prenatal and postnatal environments, genetics, and exposure to other toxic substances.

[3] Currently, there are several commonly accepted diagnostic schemes and interpretations of the diagnostic guidelines presented in the 1996 IOM report on FAS (see Resources for Further Information and Application at the end of this statement for commonly accepted diagnostic schemes providing guidelines on diagnosing ARND). This panel is not advocating any particular system for the diagnosis of ARND or the use of these alternate descriptors.

Question 2: Can ARND be differentiated from other disorders?

Alcohol is a known teratogen and is strongly associated with a range of neurodevelopmental and behavioral disorders that may affect numerous domains of functioning across the lifespan. Emerging evidence from animal and human studies suggests that there is a constellation of symptoms attributable to PAE that may include (1) neurocognitive impairments, (2) self-regulatory challenges, and (3) impairments in adaptive functioning. However, differentiating ARND from other complex neurodevelopmental disorders can be challenging due to limited available studies attempting to distinguish ARND phenotype(s) from other disorders.

Even when a history of PAE is available, diagnosing ARND and distinguishing it from other complex developmental disorders requires prudent clinical judgment and consideration of other potential causes. In the future, we anticipate that clinicians will be assisted in making this diagnosis through advances in the identification of biomarkers sensitive to the detection of significant PAE and the development of tests that are both sensitive to and specific for alcohol-induced neurobehavioral disorders. We recommend additional rigorous scientific investigation to further refine understanding of the cognitive, behavioral, neurologic, and psychiatric clinical profiles attributable to PAE, as well as of the patterns of development evidenced by individuals with PAE. We further recommend that investigations of other complex developmental disorders include inquiry about PAE to identify the contribution of PAE to the phenotypes of other developmental disorders.

Question 3: What prenatal alcohol exposure evidence is necessary for an ARND diagnosis?

An ARND diagnosis requires confirmed, significant PAE. Determination of alcohol exposure can be based on maternal self-report; the report of a spouse, partner, relative, or friend who observed the birth mother drinking alcohol during the index pregnancy; and/or documentation in medical or other records about maternal alcohol use during the index pregnancy.

Data from animal studies across multiple species confirm that, at the highest levels of alcohol exposure in the first trimester, facial abnormalities and brain maldevelopment occur in concert. However, alterations in brain development that subsequently affect behavior can occur with a range of alcohol dosages throughout gestation, even when the face and brain appear to be structurally normal. Variable patterns of maternal drinking, including binge drinking resulting in significant peak levels or sustained drinking resulting in significant cumulative exposures, may lead to differential fetal outcomes. In addition, evidence suggests that variability in both maternal and fetal characteristics affects the potential for alcohol-induced alterations in brain

development. Thus, because there is no known safe threshold for PAE, it is not currently possible to define a safe limit of alcohol consumption during pregnancy.[4]

Question 4: What signs/symptoms will be useful as screening criteria?

The U.S. Surgeon General recommends regular screening of every woman of childbearing age for alcohol use. Screening should be conducted by adult primary health care clinicians and obstetric caregivers to protect the health of women and any subsequent offspring. For children, pediatric primary health care clinicians should obtain medical records about PAE and other potential risks from the birth mother's obstetric caregiver. For children who are not living with their birth parents, clinicians should obtain any available records that may provide information about PAE or other relevant family history. Clinicians should query families in a nonjudgmental way about all risks to a child's development, including maternal alcohol use prior to and during pregnancy. We recommend that clinicians be trained regarding the most effective ways to ask about alcohol use to ensure that this practice is adopted as routine.[5] Regular screening of parental alcohol use should continue as part of the process of child health supervision and developmental surveillance.

If PAE is confirmed, primary care clinicians should be alert for signs and symptoms that can occur during the child's development. Primary care clinicians should complete a comprehensive history for any child at risk for ARND that includes questions about developmental milestones, school functioning, peer and family relationships, adaptive and self-help skills, and specific areas of impairment, and they also should conduct a physical and neurological examination. A concern identified in any of these areas warrants a referral for a complete evaluation and followup. Absence of a concern should result in continued developmental surveillance of the child, as problems related to PAE may emerge during maturation, particularly during adolescence and young adulthood when latent ARND as well as other comorbidities commonly arise.

Question 5: What are the treatment needs for those diagnosed with ARND?

Given that the manifestations of PAE are heterogeneous, vary across development, and can be lifelong, treatment plans need to be multimodal and specific to the strengths and weaknesses of the affected individual and family across the lifespan. Treatment begins with support of the affected individual and family and education on the manifestations of ARND, risks for other

[4] The 1996 IOM report on FAS describes necessary or required confirmed alcohol exposure as "a pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behavior while drinking, or alcohol-related medical problems such as hepatic disease." New data are accumulating to suggest that ARND can occur at lower levels of alcohol exposure than indicated in the 1996 IOM report.

[5] See Resources for Further Information and Application at the end of this statement for a list of commonly used screening tools for parental alcohol use.

problems, and available treatments. Treatments should draw on evidence-based practices as they pertain to an individual's specific needs. Treatment should be implemented flexibly, but with fidelity, in addressing the specific developmental strengths and weaknesses of the individual and family. Modifications of evidence-based treatments should only be considered when those treatments have been implemented with integrity over an adequate period of time and have failed to yield improvement.

Some interventions for ARND have targeted common manifestations of PAE, including problems with mathematics, attention, self-regulation, adaptive functioning and problem-solving, social impairment, and working memory. Other interventions have focused on individual and group-based skills development or training of caregivers in behavior management. Large, well-controlled behavioral intervention studies specific to ARND are needed. First, studies are needed to determine whether currently available evidence-based interventions for problems common to children without PAE yield similar benefits in children with ARND. Second, when evidence indicates a reduced or inadequate benefit, modifications of existing interventions or development of entirely new interventions need to be completed and evaluated. In addition, these research objectives also may be accomplished by assessing for PAE those participants with other mental health disorders and developmental disabilities in treatment outcome studies. Finally, these studies should target children across the developmental spectrum, with special attention directed at the periods of challenging transitions from childhood to adolescence and from adolescence to adulthood.

Some medications have been shown to effectively treat emotional and behavioral problems in children. Although there is an impression that many of these medications may be less effective in children with PAE or may lead to an atypical response, the literature is sparse and inconclusive. High-quality randomized controlled trials of medication treatments are needed for individuals across the lifespan in order to identify which medications work best for the specific problems affecting individuals with ARND.

Many of the problems experienced by children with PAE manifest as academic impairments or other problems at school. Given the limited number of educational interventions specific to children with ARND, clinicians may need to draw on evidence-based educational interventions for other disorders. For any school-based educational, medical, or mental health intervention, it is particularly important to engage educators, school health and mental health professionals, and other staff in assessing, planning, and implementing the intervention with high fidelity to enhance the effectiveness of the specific intervention plan.

Problems in self-regulation and social and adaptive functioning can manifest as early as infancy and continue throughout the lifespan. For young children, it is important to educate caregivers and early intervention providers about the manifestations of ARND as well as the usefulness of specific intervention strategies for this age group. In addition, individuals with ARND can have poor decision-making skills, placing them at risk for a range of behavioral problems that may

lead to contact with school-based professionals and other community service providers who may be unaware of how ARND can affect a child's functioning. It is therefore important to help affected individuals and families become self-advocates and to broadly educate the public and relevant professionals about behavior problems associated with ARND.

In conclusion, children and youth with PAE have a Special Health Care Need[6] and should have ongoing developmental and behavioral surveillance by their primary health care clinician in a "medical home."[7] This surveillance should continue throughout their lifespan to assess ongoing treatment and referral needs.

[6] As adopted in 1998 by the American Academy of Pediatrics (AAP), children with Special Health Care Needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. This definition originally was proposed in McPherson M, Arango P, Fox HB. A new definition of children with special health care needs. *Pediatrics.* 1998;102:137–40.

[7] The AAP defines a "medical home" as one in which the care of infants, children, and adolescents is delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. Ideally, care is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. The Affordable Care Act of 2010 endorses the medical home model throughout the lifespan. For more information, see *http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/1/184*.

Resources for Further Information and Application

Commonly Accepted Diagnostic Schemes Providing Guidelines on Diagnosing ARND:

Astley SJ. *Diagnostic guide for fetal alcohol spectrum disorders: The 4-digit diagnostic code. 3rd ed.* Seattle, WA: University of Washington Publication Services, 2004. Available online at: *http://depts.washington.edu/fasdpn/pdfs/guide2004.pdf.*

Chudley AE, Conry J, Cook JL, Loock C, Rosales T, LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Can. Med. Assoc. J.* 172(5 Suppl.):S1–S21, 2005. Available online at: *http://www.cmaj.ca/content/172/5_suppl/S1.full.*

Hoyme HE, May PA, Kalberg WO, Kodituwakku P, Gossage JP, Trujillo PM, et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine criteria. *Pediatrics.* 115(1), 39–47, 2005. Available online at: *http://pediatrics.aappublications.org/content/115/1/39.full.pdf+html.*

Stratton K, Howe C, Battaglia F. (Eds.) *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Washington, DC: National Academies Press, 1996. Available online at: *http://www.nap.edu/openbook.php?isbn–0309052920*.

Commonly Used Screening Tools for Screening Men and Women for Alcohol Use:

National Institute on Alcohol Abuse and Alcoholism. *Helping patients who drink too much: A clinician's guide: Updated 2005 edition.* Bethesda, MD: National Institutes of Health. Publication No. 07-3769, 2007. Available online at: *http://www.niaaa.nih.gov/Publications/EducationTrainingMaterials/Pages/guide.aspx*. (Related resources, most of which are available online only, include professional support resources, manuals, forms, and a slide show. An online training is approved for continuing medical education/continuing education credit.)

Other Alcohol Screening Instruments Recommended for Use With Women:

Barry KL, Caetano R, Chang G, DeJoseph MC, Miller LA, O'Connor MJ, et al., National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. *Reducing alcohol-exposed pregnancies: A report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect*. Atlanta, GA: Centers for Disease Control and Prevention, March 2009. Available online at: *http://www.cdc.gov/ncbddd/fasd/documents/redalcohpreg.pdf.*

Acknowledgments

Conference Moderator **Tom Donaldson**, Chief Executive Officer and President, National Organization on Fetal Alcohol Syndrome, Washington, DC, maintained the smooth conduct of the meeting, ensuing ample opportunity for speaker presentations and scheduled discussions.

Expert Chair **Claire D. Coles, Ph.D.**, Professor, Departments of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine; Director, Fetal Alcohol and Drug Exposure Center, Marcus Autism Center, Atlanta, GA, led the assembled experts in presenting the available scientific and clinical evidence on ARND to the panel during public sessions.

Panel Members

Chairperson **Joseph F. Hagan, Jr., M.D., FAAP**, Pediatrics Clinical Professor, University of Vermont College of Medicine and the Vermont Children's Hospital, Burlington, VT; Co-Editor of *Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents, Third Edition;* and Chair, American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, led a distinguished panel of specialists knowledgeable about developmental disorders to craft a consensus statement with practical recommendations based on these questions.

Steven W. Evans, Ph.D., Professor and Co-Director, Center for Intervention Research in Schools, Ohio University, Athens

Eva J. Klain, J.D., Director, Child and Adolescent Health, Center on Children and the Law, American Bar Association, Washington, DC

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Speakers and Topics

Overview of Topic

Alcohol-Related Neurodevelopmental Disorder (ARND): Clinical and Empirical Evidence for an Independent Effect on Behavior
Claire D. Coles, Ph.D., Professor, Department of Psychiatry and Behavioral Science and Pediatrics, Emory University School of Medicine; Director, Fetal Alcohol Program, Marcus Autism Center

Question 1: What is ARND and how is it diagnosed (classical, current schemes, in practice today)?

Part A: Evidence of Central Nervous System Neurodevelopmental Abnormalities

The Role of a Neurological Exam in the Evaluation of FASD
Sterling K. Clarren, M.D., FAAP, Chief Executive Officer and Scientific Director, Canada Northwest Research Network; Clinical Professor, Pediatrics, University of Washington, Seattle, and University of British Columbia, Vancouver, British Columbia, Canada

Biobehavioral Markers of ARND
Sandra W. Jacobson, Ph.D. [presenter], and Joseph L. Jacobson, Ph.D., Professors, Department of Psychiatry and Behavioral Neuroscience, Wayne State University School of Medicine; Honorary Professors, Departments of Human Biology and Psychiatry, University of Cape Town Faculty of Health Sciences, South Africa

The Brain in Children With FASD
Elizabeth R. Sowell, Ph.D., Professor, Department of Pediatrics, University of Southern California/Children's Hospital Los Angeles, California; Director, Developmental Cognitive Neuroimaging Laboratory, University of California, Los Angeles

Animal Models of FASD: Pathologies Inform Behavior
Susan Smith, Ph.D., Professor, Department of Nutritional Sciences, University of Wisconsin, Madison

Part B: Evidence of a Complex Pattern of Behavior and Cognitive Abnormalities

Neurocognitive Profile of Children With ARND
P.W. Kodituwakku, Ph.D., Clinical Neuropsychologist and Associate Professor, Center for Development and Disability, University of New Mexico School of Medicine, Albuquerque

Socioemotional and Mental Health Issues in Individuals Prenatally Exposed to Alcohol
Mary J. O'Connor, Ph.D., ABPP, Adjunct Professor, David Geffen School of Medicine, University of California, Los Angeles (UCLA) and Training Director, UCLA Tarjan Center for Excellence in Disabilities Education, Research, and Service

ARND Symptoms of Dysregulation and Poor Adaptive Functioning
Julie A. Kable, Ph.D., Assistant Professor, Department of Pediatrics, Emory University School of Medicine, Atlanta, GA; Assistant Director, Fetal Alcohol and Drug Exposure Center, Marcus Autism Center, Atlanta, GA

Animal Models of FASD: Focus on Behavior
Joanne Weinberg, Ph.D., Professor and Distinguished University Scholar, Department of Cellular and Physiological Sciences, University of British Columbia, Vancouver, British Columbia, Canada

Question 2: How can ARND be differentiated from other disorders?

The Role of Genetic Investigations in the Assessment of Children at Risk for FASD
Albert Chudley, M.D., FRCPC, FCCMG, Professor, University of Manitoba, Winnipeg, Canada; Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism, Canada

Differential Diagnosis of ARND: Other Toxic Exposures
Joseph L. Jacobson, Ph.D. [presenter], and Sandra W. Jacobson, Ph.D., Professors, Department of Psychiatry and Behavioral Neurosciences, Wayne State University School of Medicine, Detroit, MI; and Honorary Professors, Departments of Human Biology and Psychiatry, University of Cape Town Faculty of Health Sciences, South Africa

Ecological Factors: Influence of Diagnostic Criteria for ARND
Ira J. Chasnoff, M.D., President, Children's Research Triangle and Professor, Clinical Pediatrics at the University of Illinois College of Medicine, Chicago

Specificity of the Neurobehavioral Profile of ARND: Comparisons With Attention Deficit Hyperactivity Disorder (ADHD)

Jeffrey R. Wozniak, Ph.D., Associate Professor, Division of Child and Adolescent Psychiatry, University of Minnesota, Minneapolis [Presenter], and Sarah Mattson, Ph.D., Professor, Department of Psychology, San Diego State University and Associate Adjunct Professor, Department of Psychiatry, University of California, San Diego

ARND: Mechanisms of Phenotype Expression and Comorbidity
Larry Burd, Ph.D., Professor, Department of Pediatrics, University of North Dakota School of Medicine; Director, North Dakota Fetal Alcohol Syndrome Center and FAS Clinic, Grand Forks

Question 3: What prenatal alcohol exposure evidence is necessary for an ARND diagnosis?

Models of FASD/ARND: What Moderate Ethanol Exposure Paradigms Suggest About Fetal Alcohol Effects and Fetal Alcohol Exposure
Daniel Savage, Ph.D., Regents' Professor and Chair, Department of Neurosciences, University of New Mexico School of Medicine, Albuquerque; Director, New Mexico Developmental Alcohol Research Center, Albuquerque

What Evidence Is Necessary for an ARND Diagnosis? What Do We Know About the Effects of Low and Moderate Levels of Prenatal Alcohol Exposure?
Nancy L. Day, Ph.D., Professor, Western Psychiatric Institute and Clinic, University of Pittsburgh School of Medicine, Pennsylvania

What Prenatal Alcohol Exposure Is Necessary for an "ARND" Diagnosis?
Susan Astley, Ph.D., Professor, Center on Human Development and Disability, University of Washington, Seattle; Director, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network

Population Issues and Moderators of Risk for FASD
Philip A. May, Ph.D., Research Professor, Gillings School of Global Public Health, University of North Carolina, Chapel Hill; Adjunct Professor Of Pediatrics, Sanford School of Medicine, University of South Dakota, Sioux Falls; Professor Emeritus, Center on Alcoholism, Substance Abuse, and Addictions, University of New Mexico, Albuquerque; and Extraordinary Professor, Faculty of Health Sciences, University of Stellenbosch, South Africa

Question 4: What signs and symptoms will be useful as screening criteria?

Screening for ARND in the Context of Developmental Delay and Other Red Flags: Perspectives From Primary Care and Subspecialty Practice
Christine Loock, M.D., FRCPC, DABP, Associate Professor and Developmental and Social Pediatrician, University of British Columbia, Vancouver, British Columbia, Canada

Collaboration With Schools To Screen for ARND
Molly N. Millians, D.Ed., Special Educator Evaluator, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Atlanta, GA

The Minnesota Experience: Establishing Systems of Care for Fetal Alcohol Spectrum Disorders (FASD)—Screening, Referrals, Diagnosis, and Interventions
Mary Jo Spencer, R.N., CPNP, M.P.H., FASD Clinical Consultant, Minnesota Organization on Fetal Alcohol Syndrome; Pediatric Nurse Practitioner, University of Minnesota Physicians, Department of Pediatrics and University of Minnesota/St. Joseph's Home for Children Clinic Collaboration, Minneapolis, MN

Question 5: What are the treatment needs for those diagnosed with ARND?

What Are the Treatment Needs of Individuals With ARND and Their Families? General Overview
Heather Carmichael Olson, Ph.D., Faculty, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine; Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle Children's Hospital Child Psychiatry Outpatient Clinic, Seattle Children's Research Institute, Families Moving Forward Program

Early Intervention for Fetal Alcohol Spectrum Disorders
Blair Paley, Ph.D., Clinical Professor, Department of Psychiatry and Biobehavioral Sciences, Semel Institute for Neuroscience and Human Behavior, David Geffen School, University of California, Los Angeles

Empirically Validated Treatment Approaches for School-Age Children With FASD
Joanne F. Rovet, Ph.D., Professor, University of Toronto, Ontario, Canada; Senior Scientist, Neuroscience and Mental Health Program, Hospital for Sick Children, Toronto

Treatment Needs and Interventions for Adolescents With an FASD
Jacqueline Pei, Ph.D., R.Psych., Assistant Professor, Department of Educational Psychology, and Assistant Clinical Professor, Department of Pediatrics, University of Alberta, Edmonton, Alberta, Canada

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Disclosure Statement

All of the panel members who participated in this conference and contributed to the writing of this statement were identified as having no financial or scientific conflict of interest, and all of them signed forms attesting to this fact. Unlike the expert speakers who presented scientific data at the conference, the individuals invited to participate on the consensus panel were reviewed prior to selection to ensure that they were independent and unbiased, and not proponents of any advocacy position with regard to this topic.

Comments

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Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD)

ICCFASD (formerly called the Interagency Coordinating Committee on Fetal Alcohol Syndrome) was created in October 1996, following a recommendation in the Institute of Medicine's *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment* report that the National Institute on Alcohol Abuse and Alcoholism chair a broad Federal effort to coordinate activities associated with FAS and related health conditions. The mission of ICCFASD is to enhance and increase communication, cooperation, collaboration, and partnerships among disciplines and Federal agencies to address health, education, developmental disabilities, alcohol research, and social services and justice issues that are relevant to disorders related to prenatal alcohol exposure. (More information about ICCFASD, its mission, vision, membership, work groups, and past activities is available at *http://www.niaaa.nih.gov/AboutNIAAA/Interagency/Pages/default.aspx*.)

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FASD Resources

Several organizations are involved in ongoing research, program evaluation, and advocacy for improved diagnosis, treatment, and public awareness of FASD, including ARND. A few of these organizations are:

Centers for Disease Control and Prevention, Fetal Alcohol Spectrum Disorders, at *http://www.cdc.gov/ncbddd/fasd/index.html*.

National Institute on Alcohol Abuse and Alcoholism, at *http://www.niaaa.nih.gov*.

Substance Abuse and Mental Health Services Administration, FASD Center for Excellence, at *http://www.fasdcenter.samhsa.gov*.

American Academy of Pediatrics, at: *http://aappolicy.aappublications.org/index.dtl*.

Collaborative Initiative on Fetal Alcohol Spectrum Disorders, at *http://www.cifasd.org*.

Fetal Alcohol Spectrum Disorders Study Group, at *http://fasdsg.org*.

National Organization on Fetal Alcohol Syndrome, at *http://www.nofas.org*.

Initiative of the

Diagnostic Issues Work Group

Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders

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National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health

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