The Undiscovered Country: Why and How to Carry Out FASD Research Across the Life Span

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There is no empirical information to guide diagnosis and treatment of adults with fetal alcohol spectrum disorders (FASD). It is critically needed, and the time is now.

Nearly all publications on the effects of prenatal alcohol exposure note that the consequences are profound, and have life-long implications for the affected individual, the family and society.
Internet/Medline Search

- Searching with the term “fetal alcohol syndrome” = 2,047 hits.

- Searching with the term “fetal alcohol” = over 4,500 hits.
  Restricted to humans aged 19 and over = 709 hits, and fewer than 25 articles dealt with physical, cognitive, or behavioral outcomes.

Although FASDs have lifelong effects, and most children diagnosed with an FASD will grow into adulthood, we know almost nothing about the long-term behavioral and health consequences of this disorder.
Dr. Riley solicited stories about individuals with an FASD who were between young adult and middle aged.

More than 80 replies from all over the world yielded many success stories of employment, marriage, children, education – following troubled teen and early adult years.
Reconnect with and establish a registry of all individuals who were previously classified as having FASDs, and who participated in earlier research studies.

Purpose: By establishing a registry, these adults can be available for enrollment in future studies.

Examples include: The Seattle Fetal Alcohol Follow-up Study cohort of N=475 born before 1986. The Atlanta Longitudinal Cohort of 350 individuals born between 1980 and 1986.

Strategy: Develop a data sharing plan so that de-identified data from the registry can be available to other researchers.
In developing ideas for follow-up research, we talked with many people affected by an FASD.

We found that not only do researchers want to learn more about FASD across the lifespan -- *affected individuals and their families are desperate for more information and help as they grow older.*

*They are eager and willing to partner with committed researchers to make this happen. In fact, almost every one of the individuals with whom we talked (59/62) would like to participate in research.*
Determine the long-term health consequences of prenatal alcohol exposure. Popova et al. (2016) identified 428 comorbid conditions co-occurring in individuals with FASD.

Animal data point to an increase in negative health outcomes, and a fetal programming model (Hellemans et al., 2010; Zhang et al., 2005) provides one explanation about how prenatal exposure to alcohol might impact long-term health and behavior.

It is critical to see if results based on animal data can be replicated in humans.
Determine new ways to improve identification of FASDs in adults.

- The DSM-5 now provides a diagnostic code that can be used to identify Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) (DSM-5 pg. 86). These criteria have the potential to make diagnosis by physicians and mental health professionals more accessible for larger numbers of people.

- “ND-PAE acknowledges that PAE is associated with functional impairment and allows diagnosis based largely on observable learning and behavioral symptoms. **Systematic research is necessary to validate and refine the proposed diagnostic criteria.**”  
  Olson, 2015
DSM-5: Neurodevelopmental Disorders

- Intellectual Disability/ID (MR)
- Communication Disorders
- Autism Spectrum Disorders
- Attention-Deficit/Hyperactivity Disorder
- Specific Learning Disorder
- Motor Disorders
- **Other Specified Neurodevelopmental Disorder (ND-PAE)**
- Unspecified Neurodevelopmental Disorder.
Suggested ND-PAE Diagnostic Criteria

A. **More than minimal exposure** to alcohol during gestation

B. **Impaired neurocognitive functioning** manifested by 1 or more impairments: IQ, EF, learning, memory, visual-spatial reasoning

C. **Impaired self-regulation** manifested by 1 or more impairment in the following: mood/behavior regulation, attention, impulse control

D. **Impaired adaptive functioning** manifested by 2 or more impairments in the following: communication, social skills, daily living skills, motor skills;

E. ONSET (of symptoms B, C, and D): childhood

F. SEVERITY: clinically significant distress or impairment in social, academic, occupational, or other important areas of functioning

G. DIFFERENTIAL DIAGNOSIS: The disorder is not better explained by the direct physiological effects of substances, a medical condition (e.g., TBI, delirium, dementia), another known teratogen (e.g., fetal hydantoin syndrome), a genetic condition (e.g., Williams syndrome, Down syndrome, Cornelia de Lange syndrome), or environmental neglect.
Do brain structures (e.g. white matter, cortical thickness, regional volumes) change over time among those living with FASD?

If so, how are brain changes related to behavior and neuropsychological performance?

Next Steps: Compare brain images collected approximately 20 years ago to images (yet to be collected) from the same individuals as adults (e.g., University of Washington and Emory University cohort study participants).
“Further research is urgently needed to quantify the prenatal brain damage from alcohol. The identification and evaluation of new quantification methods should facilitate diagnosis and permit the development of more appropriate guidelines for providing needed services.”

Streissguth et al., 1996

“Brain dysmorphology is the center of the prenatal teratogenic effect of alcohol. Taking this into consideration (is) thus likely to improve the delivery of appropriate social services, as they will be more closely tailored to the actual neuroteratological basis for prognosis.”

Bookstein et al., 2001
“Effective strategies for remedial interventions appropriate to the needs of people with FAS/FAE need to be developed, evaluated, and implemented.”  
Streissguth, et al., 1996

“An approach that looks at the multiple factors that may be at play will lead to more effective and enduring benefits. Ultimately, this is an empirical question and can only be answered by systematic and rigorous research trials.”  
Systematic Review of FASD Interventions Across the Life Span, Reid, et al., 2015
Summary of Available Research Evidence

• 1981 U.S. Surgeon General Recommendation Against Use of Alcohol by Women Who Are or Plan to be Pregnant.

1996 Institute of Medicine (IOM) Report

• Recommendation to Establish the Interagency Coordinating Committee on FAS (ICCFAS).
• ICCFASD was an Organizer & Funder of the American Bar Assoc. (ABA) Training, Which Led to passage of the 2012 ABA Resolution on FASD.


1991: With federal funding from SAMHSA, Drs. Streissguth & Grant established the Parent-Child Assistance Program (PCAP). Research data confirmed PCAP is successful in preventing future alcohol and drug-exposed births.

- Since 1996: WA State DSHS has funded expansion of PCAP to 12 sites serving over 1,000 families; SAMHSA and HRSA have funded numerous sites in other states.
- In 2009 the Institute of Health Economics Consensus Development Conference in Alberta, CA recommended that a high priority be placed on prevention services for women at highest risk of having a child with FASD, and Canadian programs based on the PCAP model should be encouraged. Canadian provincial governments and First Nations and Inuit Health Branch have funded numerous sites in three provinces. WA and Canada data have confirmed cost effectiveness.
In 1993 the CDC funded the WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN) at the UW (Drs. Astley & Clarren) as a FASD primary prevention study.

- In 1995 WA State Senate Bill 5688 authorized the FASDPN statewide network of clinics with the mission of FAS prevention through screening, diagnosis, intervention, training, education, and research.
- SSB 5688 also authorized the Departments of Social and Health Services, the Office of Superintendent of Public Instruction, the Dept. of Health, and the Dept. of Corrections to create the FAS Interagency Work Group (FASIAWG) to ensure the coordination of programs serving children who have FASD, and women at high risk of having children with FASD. The legislation included the first provision in WA State history for representatives of family-run advocacy groups to participate in the planning, development, delivery, and review of services administered by these agencies.
“It is the cooperation among families, communities, government agencies, and individuals that permits a focusing of combined energies toward solutions that are beneficial to all.”


