

# Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders

## Diagnosis, Assessment and New Directions in Research and Multimodal Treatment

Editors:

**Susan A. Aduato**

University of Medicine and Dentistry of New Jersey

New Jersey Medical School

USA

**Deborah E. Cohen**

Office for the Prevention of Developmental Disabilities, New Jersey

USA

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Multimodal Treatment**

**Editor**

**Susan A. Adubato**

**and**

**Deborah E. Cohen**

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**LET US PUT OUR MINDS TOGETHER AND SEE WHAT LIFE  
WE CAN MAKE FOR OUR CHILDREN  
Sitting Bull**

*This e book is dedicated to all of our families, who continue to show us what we  
need to learn*

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## FOREWORD

This book is being published at just the right time in the history of efforts to address Fetal Alcohol Spectrum Disorders. It is not only timely but supported by the thinking of some of the most talented scientists in the field. Many, I have had the pleasure of working with and I know well their selfless dedication to this field of work.

It was 1995 when I joined the National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, as the Associate Director for Collaborative Research. My career in government began 28 years prior with the conduct of studies on the effects of thalidomide and the potential for other prescription drugs to cause unanticipated fetal damage. Unsuspecting pregnant mothers consumed thalidomide hoping to escape the discomfort of nausea and brought to term children damaged for life. I took an immediate interest in the effects of alcohol consumption on pregnancy outcomes and child development. Once again, I thought the answer would be simple. Since no one willingly and knowingly wants to harm or in any way damage their developing child, the prevention of Fetal Alcohol Syndrome (FAS) had to be a straight forward task. Simply make it known and the incidence and prevalence would be reduced; the problem eliminated. The state of the research on the cause and consequences of prenatal exposure to alcohol was clear. Case studies and population studies confirmed the findings of Jones and Smith that prenatal alcohol exposure can cause a pattern of deficits that are permanent. Many research questions remained unanswered because of the low prevalence of affected children in the United States of the same age, in the same general location, and with their birth families. A major problem at the time was in the fact that only those children with the documented distinctive facial features of FAS were being counted. With the face as the only recognized biomarker for the disorder, it was puzzling to be shown a child with normal appearance and told that he or she was affected by FAS.

The breakthrough occurred in 1997, when Dr. Denis Viljoen, a pediatrician, alerted the Institute to the high prevalence of affected children in the wine growing areas of South Africa. A site visit by research scientists from many disciplines was organized by me and Dr. Kenneth Warren, currently Acting Director of the Institute, and led by Dr. TK Li, then a distinguished Professor at Indiana University and subsequently Director of the Institute until his retirement in 2008. The resulting research and studies advanced the state of knowledge and understanding of the disorder and pointed to the need for further collaborations with the governments and research scientists in other countries. And so it went and has continued until now. Many countries have joined in the research, recognized that the problem exists in their populations, and taken steps toward prevention. There now is documentation of prenatal alcohol effects in different populations with the realization that there is truly a spectrum of effects. The most devastating is not the facial features, but the behavioral patterns and cognitive deficits that are problematic and costly for families and governments.

What is now accepted widely as Fetal Alcohol Spectrum Disorders (FASD) can be prevented. Just stop drinking during pregnancy. I have travelled to many countries and seen many pamphlets, displays and tee shirts that were developed as a prevention effort. The winner in my opinion was in South Africa. The tee shirt read, "Mommy please don't hurt my brain". It had a picture of a pregnant woman drinking alcohol with an x through the alcohol- straight forward and clearly stated. Did it work? We have yet to determine but for those who do not read pamphlets and books, it is worth a try.

I cannot overlook the contributions of the agencies that joined with NIAAA in an Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders. Representatives from Federal agencies in the Department of Health and Human Services, the Department of Justice and the Department of Education have worked tirelessly since 1997 to address FASD within the mission of their organizations. As the former Chair for this Committee, I am grateful and I am certain that the families of affected children are encouraged by the progress that has been made under the leadership of these agencies: websites were developed, state FAS coordinators met annually, grants for interventions and prevention approaches increased, a Center for Excellence for FASD was created in one agency, interventions for affected children were tested in another, numerous effective workshops and symposia were held, and teachers and physicians and social workers were alerted. This work continues.

The realization that any significant progress in research (basic and translational), in prevention, and in intervention development for FASD requires multi-disciplinary and trans-disciplinary partnerships and collaborations nationally

and internationally was a breakthrough. There are few persons on the planet who won't recall where they were on September 11, 2001 when the World Trade Center in the United States was destroyed by explosives. An international group of FASD research scientists will always remember that they were meeting in Valencia, Spain to determine the feasibility of advancing the state of research on FASD through closer working relationships between basic research scientists and those that studied affected children. They identified the research questions that were plaguing each group and left with a determination that significant progress would be made from more intensive interactions. NIAAA published requests for applications that encouraged the open exchange of information, nurtured partnerships and encouraged the formation of teams of scientists representing multiple disciplines. And this continues.

I cannot paint the picture of progress and continuing efforts without a mention of the national and international non-profit organizations that stood by the scientists and government agencies that fought and educated in the arenas and settings in which they could be effective. I especially applaud the work of the National Organization on Fetal Alcohol Syndrome. This work continues.

Again, I think this book brings it all together. It is comprehensive and well informed and it is my hope that it will be used as a teaching tool as well as renewed motivation and re-dedication to make progress for affected children and their families.

***Faye J. Calhoun***

Retired Former Deputy Director  
National Institute on Alcohol Abuse  
Alcoholism, National Institutes of Health  
Bethesda, Maryland

## PREFACE

Welcome to the first E-book on prenatal alcohol exposure and Fetal Alcohol Spectrum Disorders (FASD). When we first set out to do this E book, our intent was to compile a text that presented a past, present, and future directions perspective, but our authors had their own ideas. This book has turned out to be a look, not only at present research but, more importantly, innovations of research and clinical interventions. In addition, while the thematic basis for this E-book is the consequences of consuming alcohol during pregnancy, each chapter offers a different perspective resulting from prenatal exposures. As such, each chapter can “stand alone”. This E book provides a phenomenal opportunity in that it allows readers to “link” directly to relevant websites, and to view real time videos within the text.

Although the use of the term “FASD” was not officially accepted for general use until 2004, many clinicians in the field used it previously. Please note that many of the authors for this E book use FASD generically for their discussions regarding any prenatal alcohol exposure, even when discussing issues prior to 2004. In addition, the term “intellectual disability” has replaced the term “mental retardation”.

Our first chapter begins with an oft-times debatable topic- diagnosis. Susan Astley provides a provocative chapter on such a heated topic. Presenting the various models in use today, Dr. Astley provides the reader with the choices for diagnosing an FASD and the strengths and weaknesses of each model.

The second chapter, by Jennifer Thomas and Ed Riley, presents the fascinating and relatively new research on choline and other interventions. Drawn from basic science research, the interventions discussed seem to hold some promises for improving the effects of prenatal exposure to alcohol in the coming years.

The chapter by Natalie Novick Brown, Kieran O’Malley and Anne Streissguth addresses the challenges of diagnosing, assessing and treating psychiatric problems that are associated with prenatal alcohol exposure and co-occurring issues.

Chapters 4-6 provide a life span look at the difficulties encountered by families dealing with prenatal alcohol exposure, and some of the innovative work being done for and with our families. Heather Carmichael Olson and Rachel Montague, begin this journey with a chapter that addresses the importance of early interventions and other related issues for young children. Claire Coles, Elles Taddeo and Molly Millians discuss very interesting and innovative interventions that are assisting school aged children to reach their potential. And finally, Mary DeJoseph completes the life span approach in her discussion of the continuing needs of adolescents and adults that are exacerbated by the paucity of scientific research for, and what some of the clinicians in the field have been suggesting, are effective intervention.

Kay Kelly provides very practical approaches for navigating the sometimes difficult and confusing social and legal systems in Chapter 7.

The next chapter by Kathy Mitchell and Mary DeJoseph allows the reader to understand what it means to struggle with addiction, recovery and an FASD on a daily basis through interviews with and individual vignettes written by family members whose lives have been touched by FASD. Very little of this chapter was edited, so readers will get a firsthand account from the individuals themselves.

For the final chapter, the co-editors, Debbie Cohen and Susan Adubato present the “state of the states”: descriptions of federal programs as well as initiatives that have been undertaken in three States and Common wealth are presented. This chapter illustrates differing ways state programs have evolved to address the need for screening for prenatal alcohol consumption, FASD assessment, diagnosis and treatment, and service system enhancement. The chapter concludes with information about the role of and need for joining forces with voluntary agencies to address FASD.

The last word for the E book is a personal journey for one family and offers hope for families that their family member affected by prenatal exposure to alcohol can develop, mature, find love and success and be happy.



**Please remember: The opinions expressed in this e book are those of the individual authors, and do not necessarily reflect the views of the editors.**

All proceeds for this E book will go to further training through NOFASNJ.

We would like to thank Cara Castiglio, who works for the Southern New Jersey Prenatal Cooperative for our cover art. We also are most appreciative to Ellen Dunn, NJ Office For the Prevention of Developmental Disabilities, for her careful review of this manuscript.

The editors also would like to thank Bentham Publishers for taking a chance on this E-book, and an extra “thank you” to Bushra Siddiqui, whose patience and direction made the journey much easier.

While we both work in the field of FASD, one of the greatest benefits for us in compiling this E-book is that our knowledge of the consequences of prenatal exposure to alcohol and the possibilities of interventions and treatment grew. It is our hope that you will benefit from this E-book in similar ways and that it stimulates your interest to continue to learn more about FASD. To this end, as this book is to be produced, one new publication has been released on basic research in FASD: [Alcohol, 2011;45(1):1-104] and two recently published are: Looking at legal and justice issues for individuals with FASD [Journal of Psychiatry & Law, 2010;38(4);Winter], and Alcohol Research and [2011,34(1);summer]. Both discuss various topics and new innovations in FASD, including new developments in imaging.

***The Editors***

## CONTRIBUTORS

### **Susan Adubato**

Associate Director for Clinical Services, Division for Developmental and Behavioral Pediatrics, University of Medicine and Dentistry of New Jersey- New Jersey Medical School; Director, New Jersey/Northeast FASD Education and Research Center; Director, Northern New Jersey FAS Diagnostic Center; Assistant Professor, Departments of Pediatrics and Psychiatry, UMDNJ-NJMS, Newark, New Jersey, USA

### **Susan J. Astley**

Professor of Epidemiology/Pediatrics; Director, WA State FAS Diagnostic & Prevention Network, University of Washington, Seattle, Washington, USA

### **Faye Calhoun**

Retired, Former Deputy Director, National Institute on Alcohol Abuse and Alcoholism at NIH; Special Assistant to the Vice Chancellor for Graduate Education and Research, North Carolina Central University, Durham, North Carolina, USA

### **Deborah E. Cohen**

Former Director, New Jersey Office for the Prevention of Developmental Disabilities, Trenton, New Jersey, USA

### **Claire D. Coles**

Director, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Children's Health Care of Atlanta, and Professor, Departments of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine, Atlanta, Georgia, USA

### **Natalie Novick Brown**

Program Director, FASD Experts; Clinical Faculty, Department of Psychiatry and Behavioral Medicine, University of Washington, Seattle, Washington, USA

### **Mary DeJoseph**

Consultant, New Jersey/NE FASD Education and Research Center, UMDNJ-NJMS, Newark, NJ, USA

### **Kathryn Kelly**

Project Director, FASD Legal Resource Center, Fetal Alcohol and Drug Unit, Department of Psychiatry and Behavioral Sciences, School of Medicine, University of Washington, Seattle, Washington, USA

### **Molly N. Millians**

Special Educator Evaluator, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Children's Health Care of Atlanta, Atlanta, Georgia, USA

### **Rachel A. Montague**

Graduate Student, Department of Clinical Psychology, Seattle Pacific University, Seattle, Washington, USA

### **Kathleen Tavenner Mitchell**

Vice President, International Spokesperson, National Organization for Fetal Alcohol Syndrome, Washington, DC, USA

### **Heather Carmichael Olson**

Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle Childrens' Hospital Child Psychiatry Outpatient Clinic, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Families Moving Forward Research Program, Seattle, Washington, USA

**Kieran D. O'Malley**

Child and Adolescent Psychiatrist, Lucena Clinic, Child Adolescent Mental Health Services (CAMHS), Dublin, Ireland

**Edward P. Riley**

Director, Center for Behavioral teratology, Professor, Department of Psychology, San Diego State University, San Diego, California, USA

**Ann P. Streissguth**

Professor Emerita, Department of Psychiatry and Behavioral Sciences, Founding Director, Fetal Alcohol & Drug Unit, University of Washington School of Medicine, Seattle, Washington, USA

**Elles Taddeo**

FAS Research Education Specialist, Emory University School of Medicine, Department of Psychiatry and Behavioral Sciences, Atlanta, Georgia, USA

**Jennifer D. Thomas**

Professor, Department of Psychology, Center for Behavioral Teratology, San Diego State University, San Diego, California, USA

**CHAPTER 1****Diagnosing Fetal Alcohol Spectrum Disorders (FASD)****Susan J. Astley\****Departments of Epidemiology and Pediatrics, University of Washington, Seattle, Washington, USA**While we try to teach our children about life, our children teach us what life is all about***Angela Schwindt**

**Abstract:** Fetal Alcohol Syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. Almost four decades have passed since the term FAS was first coined. The condition is now recognized as a spectrum of disorders: Fetal Alcohol Spectrum Disorders (FASD). Substantial progress has been made in developing specific criteria for delineating diagnoses under the umbrella of FASD. In the 14 years since the publication of the seminal report on FAS by the Institute of Medicine in 1996, clear consensus has been reached on two fundamental issues: 1) an FASD diagnostic evaluation is best conducted by a team of professionals from multiple disciplines (medicine, psychology, speech-language, occupational therapy) and 2) the team should use rigorously case-defined and validated FASD diagnostic guidelines. This chapter will provide a brief overview of the discovery of FASD, diagnostic challenges, how diagnostic guidelines and clinical models have evolved over time to address these challenges, and how new technology may influence the future of FASD diagnosis.

**INTRODUCTION****What is FASD?**

Fetal Alcohol Syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The definition of FAS has changed little since the 1970's when the condition was first described and refined [1-5]. The condition has been broadly characterized by prenatal and/or postnatal growth deficiency, a unique cluster of minor facial anomalies, and central nervous system (CNS) abnormalities. FAS is the leading known preventable cause of intellectual disabilities in the Western World [6]. The prevalence of FAS is estimated to be 1 to 3 per 1,000 live births [1] in the general population, but has been documented to be as high as 10 to 15 per 1,000 in some higher-risk populations such as children residing in foster care [7,8].

The physical, cognitive, and behavioral deficits observed among individuals with prenatal alcohol exposure are not dichotomous, that is either normal or clearly abnormal. Rather, the outcomes, and the prenatal alcohol exposure, all range along separate continua from normal to clearly abnormal and distinctive [9-12]. This full range of outcomes observed among individuals with prenatal alcohol exposure has come to be called Fetal Alcohol Spectrum Disorders (FASD). Diagnoses like FAS, Partial FAS (PFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND) fall under the umbrella of FASD.

**The Diagnostic Challenge**

FASD can present a daunting, but not insurmountable challenge for diagnosis. Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to prenatal alcohol exposure and often manifest differently across the lifespan. Professionals from multiple disciplines (medicine, psychology, speech-language pathology, occupational therapy, etc.) are needed to assess and interpret accurately the broad array of outcomes that define the diagnoses. The pattern and severity of outcomes are dependent on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy), and is frequently confounded by other adverse prenatal and postnatal exposures and events.

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\*Address correspondence to Susan J. Astley: FAS DPN, Center on Human Development & Disability, Box 357920, University of Washington, Seattle WA 98195-7920, USA; E-mail: astley@u.washington.edu

In the absence of objective, accurate, and reproducible methods for measuring and recording the severity of exposures and outcomes in individual patients, diagnoses have varied widely from clinic to clinic [1,13-16]. From a clinical perspective, diagnostic misclassification leads to inappropriate patient care, increased risk for secondary disabilities [17], and missed opportunities for primary prevention [18]. From a public health perspective, diagnostic misclassification leads to inaccurate estimates of incidence and prevalence [1,14,16,19]. Inaccurate estimates thwart efforts to allocate sufficient social, educational, and health care services to this high-risk population, and preclude accurate assessment of primary prevention intervention efforts. From a clinical research perspective, diagnostic misclassification reduces the power to identify clinically meaningful contrasts between FAS and control groups and between FASD clinical subgroups like FAS and ARND [9,14,20]. Non-standardized diagnostic methods also thwart valid efforts to compare outcomes between research studies [9,10, 21].

## **DISCOVERY OF FETAL ALCOHOL SYNDROME**

Reference to the harmful effects of maternal drinking on infant outcome date back to biblical times (Behold, thou shalt conceive, and bear a son; and now drink no wine or strong drink...Judges 13:7) [22], with several remarkably comprehensive descriptions by physician groups in the 1700s and 1800s [23-25]. But several hundred years would go by before another entry would be made to the medical literature. In 1968 Lemoine and colleagues from France published an article describing 147 patients [26]. In 1970, unaware of the Lemoine publication, Ulleland and colleagues from Seattle, Washington published similar observations describing a small group of alcohol-exposed infants admitted to several high-risk maternal-child health clinics at the University of Washington [27, 28]. Dr. Ulleland's findings were accepted for presentation at the American Pediatric Society-Society for Pediatric Research meeting, held in Atlantic City New Jersey in 1970 [27]. Through a presentation to the University of Washington pediatric faculty, David Smith, M.D., a dysmorphologist, became interested in Dr. Ulleland's research. This would eventually lead to a collaborative publication in 1973 describing the pattern of outcome associated with prenatal alcohol exposure [29] and the publication that coined the term FAS [2].

### **Initial FAS Diagnostic Guidelines (1973-89)**

Progress in refining the FAS diagnosis can be traced by reviewing Clarren and Smith [4], who summarized the available clinical reports from 1973 to 1976, and the reports from the fetal alcohol workshops of the Research Society of Alcoholism in 1980 and 1989 [3,5].

### **IOM FAS Diagnostic Guidelines (1996)**

In recognition of the seriousness of FAS for the individual and society, the U.S. Congress mandated (in Section 705 of Public Law 102-321, the ADAMHA Reorganization Act) the Institute of Medicine (IOM) of the National Academy of Sciences to conduct a study of FAS and related birth defects. A seminal report was published in 1996 covering the full spectrum of issues from prevalence, diagnosis, prevention, to treatment [1]. A chapter entitled "Diagnosis and Clinical Evaluation of FAS" was included. The committee was charged with evaluating existing diagnostic criteria and formulating the best possible diagnostic guidelines reflective of current knowledge. The IOM diagnostic guidelines for FASD are presented in their entirety across Tables 1-4, as they represent an important baseline from which current guidelines evolved. The IOM committee recognized the following issues as central to delineating FASD:

1. Should a documented history of exposure to alcohol be required for a diagnosis of FAS?
2. Which physical features should be used to define the disorder?
3. Can behavioral or cognitive features be used to define the disorder?
4. Is there a role for ancillary measures (e.g., magnetic resonance imaging [MRI] in making the diagnosis?
5. Can criteria be designed to be used across the lifespan?
6. What is the relationship of so-called fetal alcohol effects to fetal alcohol syndrome?

These issues will be discussed later in this chapter as they relate to both the IOM guidelines and current guidelines.

While the IOM guidelines reflected an important advancement in FASD diagnosis: 1) the IOM committee felt “a medical diagnosis of FAS remained the purview of dysmorphologists and clinical geneticists” (page 79), and 2) the guidelines remained intentionally broad and conceptual (e.g., gestalt) rather than specific and operational (e.g., case-defined) [1].

FASD diagnosis has now advanced beyond the 1996 IOM FASD diagnostic guidelines. While areas of debate still exist, the field has reached consensus on two fundamental issues: 1) an FASD diagnostic evaluation is best conducted by an interdisciplinary team of professionals, and 2) the team should use rigorously case-defined and validated FASD diagnostic guidelines.

### **Interdisciplinary Diagnostic Approach**

The University of Washington FAS Diagnostic & Prevention Network (FAS DPN) first introduced an interdisciplinary approach to FASD diagnosis through a CDC-sponsored FAS prevention project conducted in 1992-97 [18,30-32]. Because of the complexity and broad array of outcomes observed in individuals with prenatal alcohol exposure, an interdisciplinary team is essential for an accurate and comprehensive diagnosis and treatment plan. An interdisciplinary FASD diagnostic team typically includes a medical doctor, psychologist, speech language pathologist, occupational therapist, social worker, and family advocate. Other members of the interdisciplinary team may include, but are not limited to, psychiatrists, neuropsychologists, geneticists, public health nurses, and mental health specialists.

Interdisciplinary models will necessarily vary to accommodate site-specific factors like funding, location (rural versus urban), access to services, target population, etc. The model used by the University of Washington FAS DPN diagnostic clinic targets both a general population and a high-risk foster care population. Individuals from the general population (birth to adult) are referred to the clinic by a broad array of community professionals (medical, educational, social-service, justice). In addition, all children who screen positive for the full FAS facial phenotype from the FAS DPN-Foster Care Passport Program FAS screening program [7,8] are also referred to the clinic.

The patient population served by the FAS DPN has expressed strong preference for an evaluation that can be completed in a single visit. Thus, two patients are evaluated per day, one in the morning and one in the afternoon. The interdisciplinary team includes a pediatrician, two psychologists, a speech-language pathologist, an occupational therapist, a social worker, and a family advocate. Prior to an evaluation, previous medical, school, and social records are collected by the clinic coordinator and reviewed by the lead psychologist. On the day of the evaluation, the lead psychologist presents the case to the team. The child is then assessed by the second psychologist, speech language pathologist, and occupational therapist while the caregivers are interviewed by the pediatrician and lead psychologist. Upon completion of the interview, the pediatrician conducts a physical exam of the patient. The team reconvenes to derive the FASD 4-Digit Code and compose an intervention plan. The team shares the diagnostic results and intervention plan with the family at the end of the 4-hour appointment. A single comprehensive report documenting the diagnostic outcome, all data used to derive the diagnostic outcome, and intervention recommendations are submitted to the patient’s medical record.

A more detailed description of the interdisciplinary diagnostic approach used by the University of Washington FAS DPN is presented in Clarren *et al.*, [32]. A short video of an interdisciplinary diagnostic team conducting an FASD diagnostic evaluation can be viewed by clicking on <http://depts.washington.edu/fasdnp/htmls/diagteamvideo.htm> (Fig. 1).

## Interventions for Fetal Alcohol Spectrum Disorders: Implications from Basic Science Research

Jennifer D. Thomas\* and Edward P. Riley

Center for Behavioral Teratology, San Diego State University, 6363 Alvarado Court, Suite 200, San Diego, CA 92120, USA

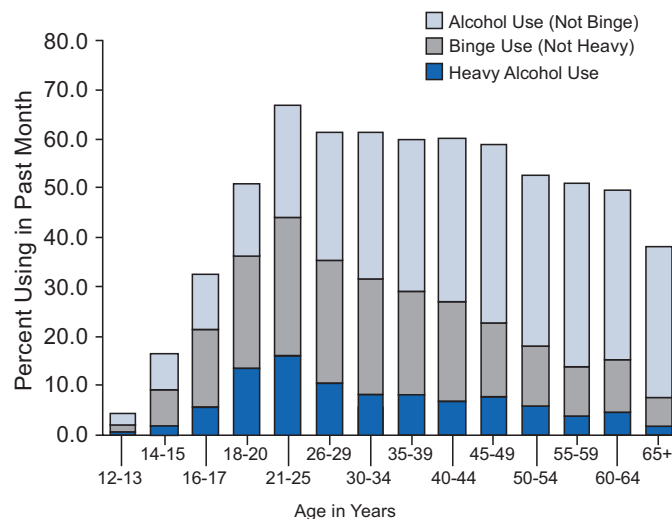
*You cannot prevent the birds of sorrow from flying over your head, but you can prevent them from building nests in your hair*

Chinese Proverb

**Abstract:** Fetal Alcohol Spectrum Disorders (FASD) constitutes a serious worldwide health problem that persists, despite prevention efforts. This chapter examines preclinical research on methods to reduce the severity of FASD, either during the period of prenatal alcohol exposure or during postnatal development. Some prenatal treatments focus on directly blocking or minimizing alcohol's mechanisms of teratogenic action. The possibility that nutritional supplements during prenatal alcohol exposure may reduce the severity of FASD is also explored. Finally, treatments that may be effective even after the alcohol insult, during postnatal development are examined, including nutritional, pharmacological, and environmental/behavioral interventions. Many exciting and effective treatments for FASD have been identified and the challenge is now to translate these findings to clinical populations.

### INTRODUCTION

Among the most common preventable developmental disorders are FAS and FASD, which may occur in over 1% of all live births [1]. Despite numerous and successful prevention efforts (see <http://www.niaaa.nih.gov/AboutNIAAA/Interagency/Reports/CurrentStudies.htm> and [http://www.fasdcenter.samhsa.gov/documents/WYNK\\_Preventing\\_FASD.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNK_Preventing_FASD.pdf)), recent data indicate that over 10% of women of child bearing age regularly engage in binge drinking [2] and 2% of pregnant women engage in risky levels of drinking [3] (Fig. 1).



**Figure 1:** Among pregnant women aged 15 to 44 in 2002, 9.1 percent used alcohol and 3.1 percent reported binge drinking in the month prior to the survey. Reprinted from Substance Abuse and Mental Health Services Administration, (2003). Overview of Findings from the 2002 National Survey on Drug Use and Health (Office of Applied Studies, NHSDA Series H-21, DHHS Publication No. SMA 03-3774). Rockville, MD.

\*Address correspondence to Jennifer D. Thomas: Center for Behavioral Teratology, San Diego State University, 6363 Alvarado Court, Suite 200, San Diego, CA 92120, USA; E-mail: Thomas3@mail.sdsu.edu

Given these numbers and the resulting large public health implications, there is a need to identify means to either block or reduce ethanol's teratogenic effects during alcohol exposure or to intervene and reduce the impact of FASD after the exposure has occurred. Although a number of clinical studies have examined or are examining interventions in high risk women of child bearing age, pregnant women consuming alcohol, as well as in individuals with FASD, the review presented in this chapter focuses primarily on preclinical, basic science research. This research has identified a number of means to attenuate the physical and functional effects seen in FASD, although in many cases the translation to clinical practice is challenging for a variety of safety and practical concerns.

## TREATMENTS DURING DEVELOPMENTAL ALCOHOL EXPOSURE

One possibility for intervening in FASD is to identify the mechanisms by which alcohol exposure might impact the developing embryo or fetus and to block those effects. Basic research has identified many potential mechanisms of ethanol teratogenesis (see <http://pubs.niaaa.nih.gov/publications/arh25-3/175-184.htm> [4]) and researchers are now basing some experimental therapeutics on these putative mechanisms. For example, ethanol has been postulated to damage the developing CNS via oxidative stress, increasing free radicals and reducing cellular antioxidant properties [5]. Numerous basic research studies in both cell cultures and whole animals have demonstrated that agents with antioxidant properties can block many of ethanol's teratogenic effects, including growth retardation, physical anomalies, and neuropathologies, including neuronal cell loss. These antioxidants include vitamin E [6], vitamin C [7],  $\beta$ -carotene [6], cyanidin-3-glucoside from blackberries [8], Pycnogenol© from pine bark [9], the superoxide-dismutase/catalase mimetic EUK-134 [10], and even the induction of Nrf2 protein which activates endogenous antioxidant enzymes [11].

However, demonstration of the effectiveness of antioxidants in animal models of FASD has not always been positive [12], and some studies show mixed results, especially regarding their effect on mitigating the behavioral outcomes following developmental alcohol exposure [13]. Of importance, a clinical study assessing vitamins C and E in mitigating the effects of prenatal alcohol exposure was terminated because of safety concerns (see [http://www.motherisk.org/JFAS\\_documents/JFAS7002\\_5\\_e3.pdf](http://www.motherisk.org/JFAS_documents/JFAS7002_5_e3.pdf)) [14]. Nevertheless, given the large number of antioxidant agents, with varying qualities and potencies, it is possible that a different level or combination of antioxidants, or induction of inherent antioxidant machinery, may prove to be more effective and safe in clinical populations.

It is important to note that some of the agents described above may exert protective effects independent of that afforded by their antioxidant properties (e.g. [8]). For example, the vasoactive intestinal neuroprotective peptides NAPVSIPQ (NAP) and SALLFSIPA (SAL) (which are derived from activity-dependent neurotrophic factor (ADNF) and activity-dependent neuroprotective protein (ADNP)) also protect against oxidative stress. Administration of these agents can reduce prenatal alcohol-induced mortality and growth deficits [15]; physical effects, including neural tube defects [16]; neuropathology, including apoptotic cell loss [17]; loss of serotonergic neurons [18], and even spatial learning deficits [19] in mice. These neuroactive peptides, however, have not shown efficacy in protecting against neuronal cell death and behavioral alterations associated with 3rd trimester alcohol exposure in rats, suggesting that their protection may depend on other factors such as the developmental timing of administration. These neuroactive peptides may also be acting via other mechanisms besides anti-oxidation [20], including protection against alcohol's adverse effects on L1 cell adhesion molecules. NAP and SAL are currently undergoing development as neuroprotectants and for the treatment of various conditions including Alzheimer's disease.

Among the mechanisms of alcohol-induced teratogenesis is the action of alcohol on L1 cell adhesion molecules, which play a critical role in axon guidance and cell migration. Specifically, alcohol, at physiological doses, impairs the ability of cells to adhere or stick to one another, and this effect is antagonized by NAP and SAL [21]. 1-octanol also acts as an antagonist of ethanol inhibition of the L1 cell adhesion molecule and has been shown to protect against alcohol-induced apoptotic cell death and gross dysmorphology in the mouse (See Fig. 2 in <http://pubs.niaaa.nih.gov/publications/arh27-2/174-180.htm>) [22].

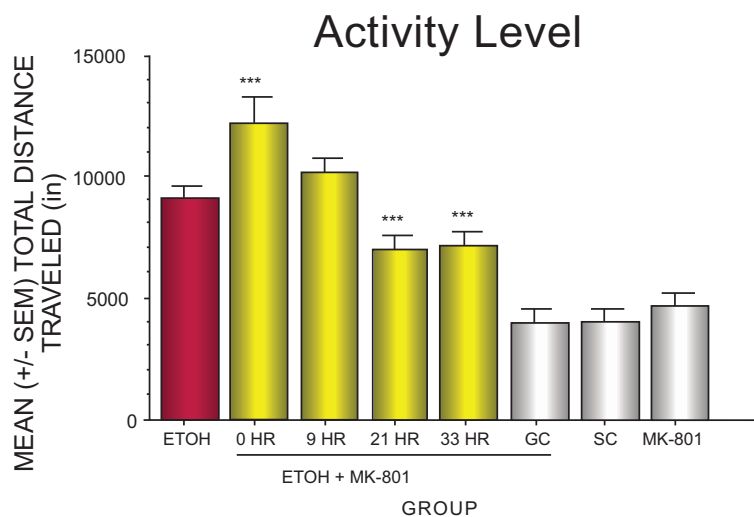
Further identification and development of targeted interventions that can protect against specific alcohol actions may prove to be fruitful.

Alcohol interacts with a number of neurotransmitter receptor sites, including the glutamatergic, N-methyl-d-aspartate (NMDA) receptor [23]. Acutely, alcohol inhibits NMDA receptors (it acts as an antagonist), which likely contributes to the



sedative and intoxicating effects of alcohol (see <http://pubs.niaaa.nih.gov/publications/arh314/310-339.htm> [24]). This blockade may, by itself, induce apoptotic cell death [25]. In addition, as a consequence of this antagonism, neurocompensatory responses, such as increased glutamate release, release of modulators like polyamines, or receptor upregulation may occur, contributing to tolerance. This results in an overly sensitive glutamatergic system once the alcohol is removed. During periods of withdrawal, the NMDA receptor may become overactive leading to excitotoxic cell death, a mechanism of cell death that is believed to occur following a number of insults, including hypoxia, stroke/ischemia, Alzheimer's disease, and alcohol-related neuropathology [26]. The developing brain is rich in NMDA receptors, as these receptors play an important role during development (<http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=frnrec&part=ch1>). However, because of this richness in receptors, it also presents a period when the brain may be more vulnerable to NMDA receptor-mediated excitotoxic cell death.

Consistent with this hypothesis, several studies have now shown that blockade of the NMDA receptor during withdrawal in the neonatal rat pup can protect against neuropathology and behavioral alterations associated with developmental alcohol exposure. The neonatal rat model is a model for human third trimester exposure, as brain development that occurs in the human fetus during the third trimester occurs in the rat during the first two weeks of life [27]. Exposure to alcohol during this period of time can produce a number of behavioral effects, including overactivity and spatial learning deficits. It has been found that MK-801, a noncompetitive antagonist of the NMDA receptor, reduces the severity of these behavioral effects, but only when administered at a period of time during ethanol withdrawal (as blood alcohol levels are approaching 0 mg/dl) [28]. MK-801's effects are dose-dependent, with lower doses (<0.5 mg/kg), but not a high dose (1.0 mg/kg), being effective [29], and time-dependent [30].



**Figure 2:** Alcohol exposure during early development significantly increased the total distance traveled in an automated open field (ETOH) compared to control groups (GC, SC). Administration of MK-801, an NMDA receptor antagonist exacerbated ethanol-related overactivity when administered at the same time as alcohol, but significantly attenuated ethanol-induced overactivity when administered during withdrawal (21 and 33 hr post-ethanol). MK-801 by itself did not significantly affect activity level. \*\*\*= significantly different from other groups.

As can be seen in Fig. 2, if MK-801 is administered at the same time as the alcohol or while the blood alcohol levels are still high, it exacerbates the effects of the alcohol exposure, but if it is administered during withdrawal, it protects against alcohol-related behavioral alterations. Such characteristics limit the clinical use of MK-801; nevertheless, other NMDA receptor antagonists may be more suitable candidates for intervening in pregnant women or for neonates undergoing withdrawal. For example, ethanol targets NMDA receptors that contain 2B subunits (each NMDA receptor comprises a 1 subunit and a combination of four various 2 subunits (a-d), the same receptors that are modulated by polyamines). The administration of eliprodil, which antagonizes the NMDA receptor at the polyamine modulatory site, during developmental alcohol withdrawal, has also been shown to reduce the severity of spatial reversal learning deficits [31] (see Fig. 3). Similarly, blockade of the NMDA receptor polyamine modulatory site with agmatine during withdrawal also protects against cerebellar-related motor deficits, indicating that antagonism of NMDA receptors may protect against a wide variety of neuropathology and behavioral alterations [32].

**CHAPTER 3****FASD: Diagnostic Dilemmas and Challenges for a Modern Transgenerational Management Approach****Natalie Novick Brown<sup>1,\*</sup>, Kieran O'Malley<sup>2</sup> and Ann P. Streissguth<sup>1</sup>**

<sup>1</sup>Fetal Alcohol and Drug Unit, Department of Psychiatry and Behavioral Sciences School of Medicine, University of Washington, Box 359112, Seattle, Washington, 98195-9112, USA and <sup>2</sup>Lucena Clinic, Child Adolescent Mental Health Service (CAMHS), Exchange Hall, Tallaght, Dublin 24, Ireland

*May the enduring spirit of Michael Dorris light the evolution of our understanding*

**Kieran O'Malley**

**Abstract:** For approximately 40 years, Fetal Alcohol Spectrum Disorders (FASD) has been defined consistently in terms of three diagnostic features in the presence of prenatal alcohol exposure: two physical criteria (*i.e.*, dysmorphic face and growth deficits) and central nervous system dysfunction (structural, neurological, and/or functional). Despite this relatively long and intact diagnostic history, identifying FASD has been difficult historically due to the complexity of presenting symptoms, varied handling by different diagnostic schemes, need for multidisciplinary assessment, and the masking of neurodevelopmental symptoms behind psychiatric diagnoses (“co-occurring disorders”). The objectives of this chapter are threefold: (1) to summarize diagnostic schema and characteristics of children and adults with FASD; (2) to increase awareness of some of the diagnostic challenges that currently exist in FASD assessment, particularly in terms of co-occurring disorders; and (3) to recommend a model standard of multidisciplinary assessment and multimodal treatment that may be useful to professionals in the clinical setting.

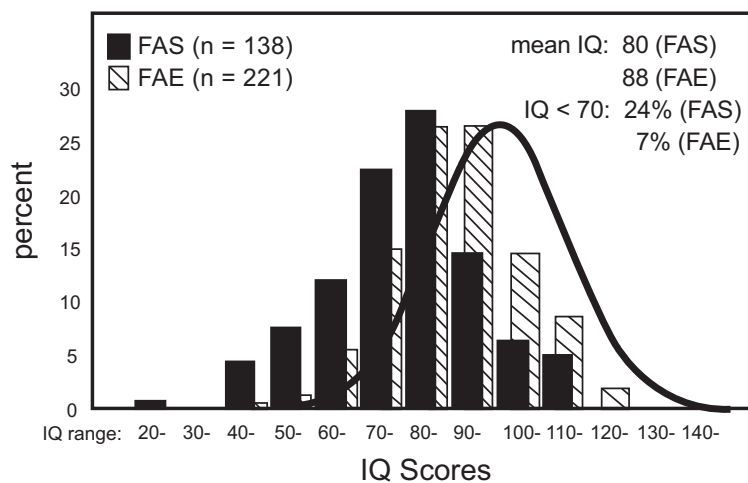
**HISTORICAL OVERVIEW**

Fetal Alcohol Syndrome (FAS) was initially described by Lemoine and colleagues in a regional French medical publication [1]. It was independently re-discovered in Seattle, Washington [2,3], by medical researchers who reported similar physical and growth anomalies and central nervous system (CNS) disorders in a small group of children born to alcoholic mothers. The early diagnoses were made by dysmorphologists who were experts in birth defects and physical anomalies, many of which had genetic origins, but some also derived from environmental etiologies [4]. Early on, FAS was identified by characteristic physical anomalies (particularly of the face), growth deficiency, and some central nervous system deficits. Shortly before his death, David W. Smith made a plea for recognition of a wider spectrum of offspring damage caused by prenatal alcohol exposure, which he termed “Fetal Alcohol Effects” (FAE) [5]. Sixteen years later, the Institute of Medicine (IOM) studied FAS and came up with a new term “Alcohol Related Neurodevelopmental Disorders” (ARND) to describe persons who did not have the full FAS but had behaviors shown to be associated with prenatal alcohol exposure that could have been caused by prenatal alcohol exposure [6]. More recently, the term “Fetal Alcohol Spectrum Disorders” (FASD) was designated as an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis, according to the “Consensus Statement on FASD” (April 7, 2004) agreed upon by representatives of the lead agencies in the field (National Institute on Alcohol Abuse & Alcoholism (NIAAA); Centers for Disease Control and Prevention (CDC); National Organization on Fetal Alcohol Syndrome (NOFAS); Substance Abuse and Mental Health Services Administration (SAMHSA), including Center for Substance Abuse Prevention (CSAP); and several FAS scientists) [7]. (The term FASD had been used earlier by Streissguth and colleagues) [8]. The term “Partial Fetal Alcohol Syndrome” (PFAS) has been used more recently by dysmorphologists to identify children in epidemiologic studies [9], as has a similar term: “incomplete Fetal Alcohol Syndrome” [10].

\*Address correspondence to Natalie Novick Brown: Dept. of Psychiatry & Behavioral Sciences, Box 359112, University of Washington, Seattle, Washington, 98195, USA; E-mail: fstnat@yahoo.com

The dysmorphology approach to identifying FAS has been effective in clinical settings where there are adequate numbers of dysmorphologists, geneticists, and specially trained pediatricians, as well as in epidemiological studies where experienced dysmorphologists trained local pediatricians to diagnose FAS (eg, South Africa [11], Italy [12], Russia [13], and with Native Americans [14]). Hoyme and colleagues [15] expanded the IOM guidelines by setting specific criteria for the facial features, growth deficiency, and brain/head circumference criteria in FAS and Partial FAS, as well as defining ARND from a practical standpoint. The intent was that these proposed revisions would provide criteria useful for clinical pediatric practice. However, the lack of adequate dysmorphology/genetic coverage for identifying and diagnosing patients with FASD of various ages led to another diagnostic system, which presumably could train teams of evaluators to evaluate and make recommendations for patients with FASD conditions within a given community using a 4-digit code [16]. Currently, both systems are in use, but to this date, many children with FAS still are never identified, and they and their communities suffer as a result.

As more children and adults with FASD were identified, it became apparent that there was a very wide range of intellectual functioning among patients with this diagnosis [17] and that, in general, there was a relationship between severity of physical findings and intellectual deficiency.



**Figure 1:** IQ scores in FASD from Streissguth *et al.* 2004 (JDBP).

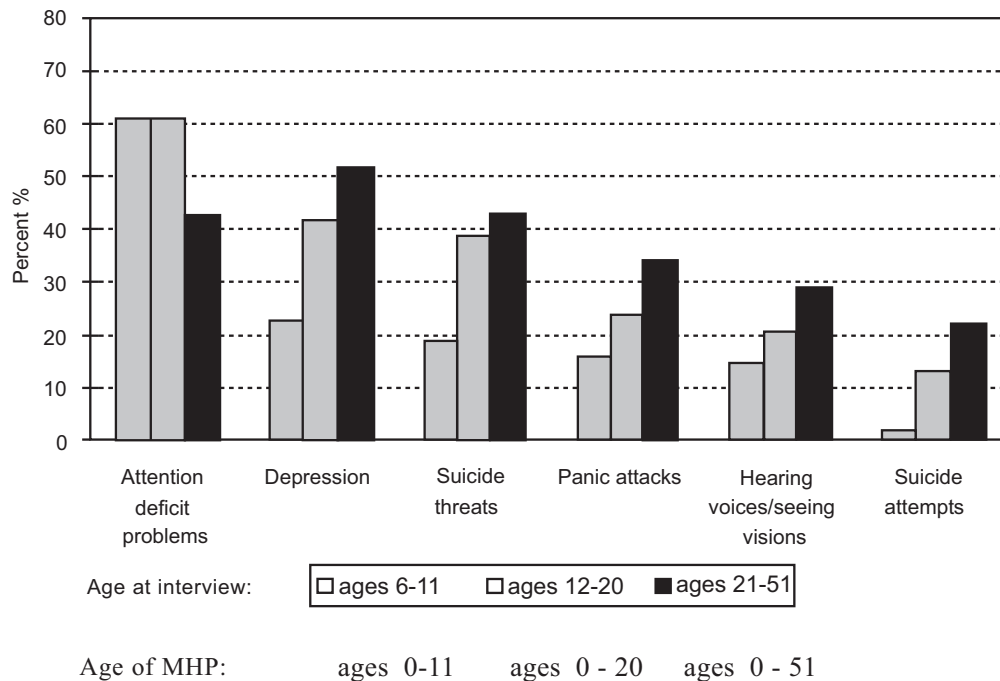
Fig. 1 [17] shows an IQ distribution of 359 patients diagnosed with FAS or FAE by dysmorphologists. As shown, patients identified with FAE had somewhat higher IQ scores in general than those identified as FAS (FAE mean IQ=88 vs. FAS mean IQ=80), but the overlap was considerable. As the usual cutoff score for developmental disability services is an IQ < 70 in conjunction with other deficits in adaptive functioning, it is clear that only 24% of this large group of patients diagnosed by dysmorphologists with full FAS would easily obtain services in their communities based on their intellectual disability, and only 7% of those with FAE would so qualify. Despite their apparent developmental disabilities, it is clear that patients with FASD are not, as a group, distinguishable by their intellectual disability.

Despite the utility of dysmorphological signs and IQ tests as a means of describing patients with FAS, these two “yardsticks” have seldom served as a basis for understanding the full impact of prenatal alcohol on the developing offspring, particularly across the age span. The first large scale study of 61 adolescents and adults with FASD [17] found that the faces were less distinctive after puberty, but the patients tended to remain short and microcephalic, although their weight became somewhat closer to the mean with increasing age, and a few were frankly obese. Average intellectual functioning was at the second-to fourth-grade level, with arithmetic deficits the most characteristic learning disability. Maladaptive behaviors such as poor judgment, distractibility, and difficulty perceiving social cues were common. Family environments were remarkably unstable: 69% of the birth mothers were known to be deceased. Of the many behavioral adjustment scales evaluated, the Vineland Adaptive Behavior Scales (VABS) was most effective in terms of measuring FASD functional deficits. The 24 diagnosed patients who received the VABS had a mean chronological age of 17 years and were functioning in general at the 7-year old level. This first study of adolescents and adults with FAS concluded that “Fetal Alcohol Syndrome is not just a childhood disorder: there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management” [17].

**CO-OCCURRING DISORDERS**

In a larger study focused on “secondary disabilities” (problems that presumably patients were not born with but appeared as life course problems as they matured), 415 patients with FAS/FAE were examined, (median IQ = 86, IQ range from 29-126) [18,19]. Life span prevalence of “Disrupted school experiences” was 61%; “Trouble with the law” was 60%; “Confinement in detention, jail, prison, or a psychiatric or alcohol/drug inpatient setting” was 50%; “Repeated inappropriate sexual behaviors” was 49%; and “Alcohol/drug problems” was 35%. Over 90% of these patients displayed co-occurring mental health disorders. The home lives of these patients were not stellar: 80% were not raised by their biological mothers, and 72% were reported to have experienced sexual or physical abuse. In this large study, the patients ranged in age from children to adults. Those with FAS had an average IQ of 78, while their average Composite standard score on the VABS Adaptive Behavior Scale was 61. A similar discrepancy held for those with FAE: average IQ was 90, but average Adaptive Behavior Composite was 67. The Adaptive Behavior Composite score is often a better predictor of life course outcomes than the IQ score. Recent follow-up studies of patients with FASD in Germany describe adolescents and adults not unlike ours but who display almost a total absence of “Trouble with the law”, presumably due to the stronger social net, and better training programs and living situations that are available for persons with disabilities [20,21]. In one of the first studies of FAS among youth in the criminal justice system, Fast and colleagues in British Columbia found that 23% could be diagnosed with FASD [22].

Secondary disabilities and co-occurring disorders in patients with FASD should be considered in light of not only the brain damage caused by the prenatal alcohol which are documented in many studies [23-29] but also the environmental circumstances often accompanying female alcoholism. In one large study by Streissguth and colleagues [18,19,30] in which mothers, parents, or caretakers of 415 patients with FAS/FAE were queried about a variety of behavioral problems, by far the most prevalent problems reported were mental health conditions. Over 90% of these 415 patients diagnosed with FAS or FAE had been to a mental health provider for help, with the proportion remaining the same across three age groups: children, adolescents and adults. Attention deficit problems were the most prevalent condition among children and adolescents (60%), while Depression was the most prevalent mental health disorder among adults (52%).



**Figure 2:** From Streissguth *et al.* 1996 Secondary Disabilities Report to the CDC.

Fig. 2 [18] shows the most prevalent mental health problems for each of the three age groups [18,31] found a similarly high rate of mental health disorders among 62 adults with FASD: 92% had a mental health diagnosis, including 65% with ADHD, 45% with depression, and 21% with panic disorder. This preponderance of mental

## An Innovative Look at Early Intervention for Children Affected by Prenatal Alcohol Exposure

Heather Carmichael Olson<sup>1,\*</sup> and Rachel A. Montague<sup>2</sup>

<sup>1</sup>Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle Children's Hospital Child Psychiatry Outpatient Clinic, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Families Moving Forward Research Program, Seattle, WA, USA and <sup>2</sup>Seattle Pacific University, Department of Clinical Psychology, USA

### From Parents of Children with FASD:

*"That's the whole idea... early intervention so we can catch the problems in those [first] difficult years..."*

*"So, when our kids are little and we have an [intervention] program, then we would have structure and know the way to handle things right from the start."*

**Abstract:** Early intervention is vital for children born affected by prenatal alcohol exposure, and may take advantage of 'plasticity' in the developing brain. Early diagnosis is associated with more positive life outcomes among those with FASD. Early intervention leads to better child and family outcomes in populations with similar challenges and, in initial research, to improved outcomes among those with prenatal alcohol exposure. This chapter begins with a 'neurodevelopmental viewpoint,' central to thinking about early intervention with this population. This viewpoint emphasizes 'brain-based difficulties' arising from alcohol's teratogenic effects, and the need to reduce risks and increase protective factors. Current research on child and family strengths and deficits, and the necessary step of early identification, are reviewed. Treatment recommendations from expert professional opinion and the collective family wisdom, and findings from the few studies of early intervention in this population, are provided. To spark research progress in the field, a variety of promising existing early interventions are discussed, including ideas for needed adaptations. Links are provided to websites, parent support information, training topics for early intervention providers, and new data on behavior regulation in young children with FASD. Early intervention is an exciting research direction for the field of FASD.

## INTRODUCTION

### A Real-Life Scene Between a Young Boy with FASD and His Mother:

His mom asks: *"What should people know about working with kids like you?"*

The boy groans and says: *"We have to have another talk about how my brain works?"*

His mom explains there is a book being written about kids like him and that people interested in FASD will read this book. He jumps up on the bed with his arms outstretched and head thrown back, and yells: *"This is FANTASTIC mom!"*

The boy says: *"They should know how to help our brains work really hard. It would be like I told them a secret of how to help and they got it!... We need to be working together to make things better for me and other people..."*

They talk more, and then the boy says: *"I feel like I am in the center of the world and I am part of the world. I am happy to be me!"*

—Ian, age 8

\*Address correspondence to Heather Carmichael Olson: 2001 Eighth Avenue, Suite 400, Seattle, Washington, 98121, USA; Fax: (206) 884-7801; E-mail: heather.carmichael\_olson@seattlechildrens.org; quiddity@u.washington.edu

**Sending this to the Authors, the Mom Writes About Her Son:**

*“[This conversation] reaffirmed to me how truly insightful he is about himself and his place in this world.”*

**–Ian’s mom**

Children born prenatally alcohol-exposed come into the world with personal strengths, but also with biological vulnerabilities. Children who are affected by their prenatal alcohol exposure can show significant neurodevelopmental disabilities, even in the early years. These disabilities often go unidentified or misunderstood, but actually can be clinically diagnosed within a set of conditions collectively called Fetal Alcohol Spectrum Disorders (FASD). Early diagnosis, before age 6 years, has been identified as one of the most important ‘protective’ factors associated with greater odds of positive long-term outcomes for individuals with FASD [1]. Intervention provided in the early years has been shown to improve child and family outcome in the very few studies of children born prenatally alcohol-exposed carried out so far.

Early intervention has also been effective for other groups of children who experience similar life challenges, or have deficits like those who are affected by prenatal alcohol exposure. These include children who show developmental disabilities, polydrug exposure, traumatic brain injury, disruptive behavior disorders, and also children at high psychosocial risk or who have been maltreated. Early intervention is important, because it has the potential to take advantage of the newly understood plasticity of the developing brain to improve at least some of the neurological impairment resulting from alcohol’s teratogenic effects.

There is a general lack of intervention research focused on children affected by prenatal alcohol exposure or known to have FASD, even though interest in this topic is rapidly growing [2-4]. This is especially true for intervention with very young children. Accordingly, this chapter reviews the small amount of available treatment outcome data for young children born prenatally alcohol-exposed, but focuses more on exploring some of the existing early intervention ideas and approaches that hold promise for this surprisingly large population of young children (birth to 8 years) and their families. The chapter emphasis is on treatments that improve children’s early development or aim to improve care giving and family outcome. There is a special focus on treatments that improve children’s behavioral regulation, given the importance of this early developmental achievement for overall life success.

Readers of this chapter will find information about how to look at the problem of FASD using a ‘neurodevelopmental viewpoint’ to better understand this disability. They will learn about the ins and outs of early identification, and explore treatment recommendations coming from experts (found in a clinical database) and from the wisdom of families (found in a review of personal exchanges over the internet). Readers of this chapter will also learn about a variety of promising approaches to early intervention for this population, and think about how they can use these ideas in their own area of practice to help children with FASD and the families that care for them.

**A NEURODEVELOPMENTAL VIEWPOINT**

In designing interventions for young children affected by prenatal alcohol exposure, or with FASD, an important first step is to change perspective. This means taking a ‘neurodevelopmental viewpoint.’ This viewpoint is based on research that explains the teratogenic effects of alcohol, the collective experience of families and researchers, and several important developmental theories. This viewpoint is also based on principles from ‘developmental psychopathology’— a scientific field that explores the developmental influences on the life pathways children follow that lead to typical or atypical developmental outcomes. Taking this neurodevelopmental viewpoint can make it easier to see when certain types of intervention are not appropriate, or how to adapt treatment approaches (and change expectations) to increase effectiveness. This viewpoint is the foundation for a positive parenting intervention specialized for families raising children with neurodevelopmental disabilities (especially FASD) called the ‘Families Moving Forward Program’ [5(study #5)], discussed later in this chapter. The neurodevelopmental viewpoint and intervention basics have previously been discussed in depth as they apply to early intervention by Olson and her colleagues [6]. Many pioneering researchers and clinicians have led the way to developing this viewpoint and intervention ideas for this population [7-12].

Researcher Kodituwakku has recently presented his own neurodevelopmental framework, based on cognitive neuroscience principles, to guide development of skills-teaching interventions for children with FASD [13]. While there are differences from the viewpoint presented in this chapter, Kodituwakku's framework leads to some of the same conclusions about intervention in the field of FASD. Among these are the importance of paying attention to a child's cognitive-behavioral profile when designing interventions, and the central need to provide training on self-regulation as early as possible.

### **“Brain-Based” Difficulties**

Alcohol is a neurobehavioral teratogen. A great deal of research shows that prenatal alcohol exposure is a risk factor that changes how the fetal brain and central nervous system develop, and that these changes result in functional difficulties that start early and persist lifelong. A central idea in thinking about individuals affected by prenatal alcohol exposure, including those with FASD, is that they have ‘brain-based’ difficulties in cognition, learning and memory, or what might be called a generalized deficit in processing complex information [14,15]. These difficulties may be misinterpreted (at least in part) as disruptive or dysfunctional behavior. In young children, brain-based difficulties can often be seen as problems or delays in behavior regulation. This can include negative affect and difficulties in arousal regulation, stress reactivity, impulse control, sensory integration, early attention skills, sleep and more. They may also show difficulties in fine and gross motor function, and in coordination and balance. These underlying neurodevelopmental problems may be called ‘primary disabilities’ [7]. Observed in the day-to-day life of young children, these disabilities also show up as markedly lowered adaptive function (children's ability to communicate, get along with other people socially, and do daily living skills). Further, these may show up as lifestyle problems for young children, including social skill deficits, difficulties in pre-academic and early academic achievement and, quite distressing to care givers, challenging and often disruptive behavior.

### **Intervention Basics**

When working with those affected by prenatal alcohol exposure, or with FASD, it is vital for care givers and clinicians to go through a process of ‘reframing’ their understanding of the child's behavioral difficulties as, at least in part, ‘brain-based.’ This has been highlighted as a central intervention principle by Olson and her colleagues [5], and pioneering clinician Malbin [9]. The earlier the process of reframing can take place, the more likely it is thought that a good outcome will occur. Reframing helps parents gain a more positive view of their child, and of the parent-child relationship, which can help jumpstart the use of the most appropriate care giving methods, and move everyone down a more positive life path. The field of developmental disabilities refers to this process of reframing as gaining a more positive ‘cognitive appraisal,’ while the important framework of attachment theory calls this gaining a more positive ‘relational schema.’ Once the basic process of reframing has begun, it becomes clear to a care giver that many of a young child's learning and behavior problems are ‘brain-based.’ It is then easier for a care giver to have a more positive and realistic view of the affected individual, feel more effective, and be motivated and ‘ready to change’ their own ways of doing things. This can be true for parents, grandparents, school staff, and even daycare providers and coaches.

In addition to reframing, clinicians and researchers have come up with basic intervention processes that seem to be the ‘heart’ of what works with individuals affected by prenatal alcohol exposure, or with FASD, and their families. These intervention processes are part of the practical positive parenting intervention designed for families raising children with FASD, discussed later, called the “Families Moving Forward” program.

As a first line of treatment, it is logical for care givers to use methods that take into account these brain-based difficulties, and help improve how well the affected individual fits into his or her environment. Olson and her team use the term ‘accommodations’ for these care giving methods [5]. Accommodations include a wide variety of environmental modifications, many learned from research on ‘cognitive rehabilitation’ for individuals with traumatic brain injury. Some accommodations apply to most affected individuals, including young children, such as increasing structure and predictability in school or home routines, and making sure there is a high level of supervision [16]. These accommodations are geared to the child's ‘developmental age’ rather than chronological age. There are some accommodations that must be tailored to the needs of the particular individual with FASD. One example for young children might be a teacher who provides memory aids to a child who has problems remembering everyday information. Another example, used for a child who has trouble processing what they hear,

## Innovative Educational Interventions with School-Aged Children Affected by Fetal Alcohol Spectrum Disorders (FASD)

Claire D. Coles\*, Elles Taddeo and Molly Millians

*FASD Center at the Marcus Autism Center, 1920 Briarcliff Road, Atlanta, Georgia, 30329, USA and Departments of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine, 1256 Briarcliff Road, Atlanta, Georgia, 30306*

*Every student can learn, just not on the same day, or the same way*

George Evans

**Abstract:** Fetal Alcohol Spectrum Disorders (FASD) has been estimated to affect as many as one in 100 children. Children with prenatal alcohol exposure may exhibit physical alterations and compromised cognitive functioning. The neurodevelopmental deficits associated with FASD range from global intellectual impairments to specific processing deficits, and learning disabilities that can hinder academic performance and adaptive functioning. The purpose of this chapter is to provide an overview of the impact of FASD on children's education, and to present a brief summary of the evidence-based programs and other interventions that may support better educational and behavioral outcomes for alcohol-affected children.

### INTRODUCTION

Fetal Alcohol Syndrome (FAS) and the spectrum of associated conditions that result from maternal alcohol use during gestation (*i.e.*, Fetal Alcohol Spectrum Disorders, FASD) are among the most common developmental disorders and may affect as many as one in 100 children [1,2]. The prevalence of FASD is higher than, or similar to, the prevalence of other common developmental disabilities, such as Down syndrome, Spina Bifida, Autism Spectrum Disorder (ASD), and Fragile X [3]. Thus, it is a concern that, although the prevalence of FASD is similar to other developmental disabilities, there has been much less attention paid to investigating educational functioning and interventions for alcohol-affected children [3].

Children most severely affected by alcohol receive a clinical diagnosis of FAS, and display physical characteristics such as dysmorphic facial features and growth deficits, as well as evidence of the neurocognitive impact of their prenatal exposure. Cognitive impairments also are associated with Fetal Alcohol Spectrum Disorders (FASD) although the physical features may not be apparent. These cognitive impairments can range from global intellectual deficits to specific processing and academic deficits that interfere with children's success in school [4]. Often children diagnosed with alcohol-related disabilities have behavior and emotional problems as well. Such problems may be the result of the effects of their prenatal exposure or of non-optimal postnatal environments; or, as is most likely, of the interaction of these factors. Thus, the alcohol-affected child comes to the learning environment with a number of challenges. Given the spectrum of outcomes associated with an alcohol-related diagnosis, it is important for teachers, professionals, and caregivers working with children with FASD to understand the range of these effects and their impact on learning.

This chapter presents an overview of the educational needs of, and interventions for, children with alcohol-related diagnoses. In addition to the research on the cognitive and behavioral effects of prenatal alcohol exposure, the information for this chapter is compiled from the limited available research that has investigated educational interventions for children with FASD and clinical observations from professionals working with children with an alcohol-related diagnosis. We have also taken into account insights from the extensive body of research into the efficacy of interventions for children with other developmental disabilities which may have overlapping characteristics [5,6]. The first goal of this chapter is to provide information about the impact of the consequences of the neuro developmental

\*Address correspondence to Claire D. Coles: Departments of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine, 1256 Briarcliff Road, Atlanta, Georgia 3030, USA; E-mail: Claire.Coles@choa.org



effects of alcohol and of environmental experiences on the learning and achievement of children with FASD. To do so, the authors will first outline specific cognitive and academic problems observed in children with FASD, and then provide a discussion of interventions. This discussion will include a review of several studies that have investigated interventions to improve academic, social, and adaptive skills in children with FASD. Additionally, the authors will provide suggestions for interventions found to be useful in clinical settings for children with FASDs and with other developmental disabilities that share similar cognitive profiles as children with an alcohol-related diagnosis.

## **NEURODEVELOPMENTAL DELAYS ASSOCIATED WITH PRENATAL ALCOHOL EXPOSURE AND ENVIRONMENTAL CONDITIONS THAT IMPACT LEARNING**

In 1973, Kenneth Lyon Jones' and David Smith's article "Recognition of Fetal Alcohol Syndrome in Early Infancy" was published in the journal, *Lancet* [7]. The article described the impact of gestational alcohol exposure on offspring. Since the publication of the Jones and Smith article, many studies have taken place confirming the effects that were reported and expanding the understanding of these disorders in children. Over time, it has been recognized that prenatal alcohol exposure may lead to a spectrum of effects including the clinical diagnoses of Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS) [8] as well as a number of outcomes that are summarized by the term FASD. Although it is not a diagnostic term, the phrase Fetal Alcohol Spectrum Disorders (FASD) is currently used in most literature.

Until recently, FASD research focused almost exclusively on the prevention of the consequences of maternal alcohol abuse by encouraging abstinence in pregnancy and, when observing children, on the neurodevelopmental and physiological deficits in offspring. Some of these effects and their educational implications are summarized in Table 1. It is evident that deficits are widespread and have the potential to affect children's academic achievement. In the last decade, neuroimaging research has confirmed in human samples what was obvious from animal models: that alcohol affects the structure of the brain and these alterations probably account for many later learning problems [9]. The size and function of the frontal cortex are affected [9-11] and this difference may be associated with problems observed in working memory, complex problem solving, and abstract thinking [2,12-15]. Several researchers have found abnormalities in gray and white matters in the brain, and in some individuals with FAS, the corpus callosum was greatly diminished or missing [16-19]. Even when the corpus callosum is intact, there is evidence that white matter is diminished, a condition that could affect the efficiency of information processing [20-22]. Other studies report that the hippocampus, which is known to be associated with learning and memory, is smaller in alcohol-affected individuals [23, 24].

Behavioral effects of prenatal alcohol exposure have been documented both clinically and through a number of research studies [25,26]. Children with FASD may exhibit IQ scores ranging from 45 to 110 (with averages of 65 to 67) [27,28]. Children who are affected by prenatal alcohol exposure but do not meet the criteria for a diagnosis of FAS may have higher general intellectual functioning, yet have a variety of learning deficiencies.

White matter damage to the brain may impair encoding of verbal and visual information and affect processing speed [20]. Additionally, deficits in visuo-spatial skills and problems with executive functioning are associated with gestational alcohol exposure [21,29-32]. Executive functioning encompasses the abilities to plan, to execute, to shift problem solving techniques, and to monitor and adjust the thinking processes. Additionally, executive functioning incorporates the process of cognitive flexibility and efficiency [33-35]. Impairments such as those associated with the effects from prenatal alcohol exposure often lead to secondary learning difficulties [36].

Although it is shown that prenatal exposure to alcohol can affect neurodevelopment, this is not the only risk faced by children whose mothers drink during pregnancy. Frequently, women who use alcohol also use other substances, most often tobacco, and in some cases have other social problems and/or mental health issues. They may also associate with other individuals with substance abuse problems. Thus, the environment provided by caregivers who have problems with chronic substance abuse can also be a source of risk to alcohol-affected children. Though many studies have investigated the impact of environmental neglect on children, only a few have focused specifically on the impact of the environment on children with FASD [37-39]. However, children with FASD have neurodevelopmental vulnerabilities that may be confounded by environmental deprivation. Risks include neglect, abuse, continued parental substance use, and multiple home placements that can negatively impact children's intellectual development as well as acquisition of language, early learning skills, and behavior [38, 40-43]. It may be due to such risk factors that a recent study conducted in Canada found that children with FASD reported a significantly lower quality of life in comparison to a control group of children with various types of cancers [44].

**Table 1:** Processing Impairments Associated with FASD and the Potential Impact on Learning

<b>Impairment</b>	<b>Impact on Functioning</b>	<b>Displayed at School</b>
<b>Speed of Processing</b> [20]	<ul style="list-style-type: none"> <li>• Slow rate of intake of information</li> <li>• Slow rate of output of information</li> </ul>	<ul style="list-style-type: none"> <li>• Inconsistent grasp of information presented in the classroom</li> <li>• Misses relevant information due to poor grasp of intake</li> <li>• Slow production of work</li> </ul>
<b>Encoding of Visual Stimuli</b> [4,45,46]	<ul style="list-style-type: none"> <li>• Poor registration of visual information into the memory system - hinders visual recall</li> <li>• Difficulties with integration of information</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties interpreting information and forming conclusions due to their retention of partial intake</li> <li>• Inconsistent learning; requires extended exposure</li> </ul>
<b>Visuo-spatial Abilities</b> [32,47,48]	<ul style="list-style-type: none"> <li>• Problems with organizing visually presented information</li> <li>• Poor judgment of distance</li> <li>• Difficulties scanning a page from left-to-right, top-to bottom</li> <li>• Difficulties orientating an object and/or themselves in a mental or physical space</li> <li>• Difficulties reconstructing an image or object from a given model</li> <li>• Difficulties with reconstructing an image or pattern from memory</li> <li>• Difficulties remembering sequences of visually presented objects</li> <li>• Poor mental manipulation of object to solve a problems</li> <li>• Inefficient use of visual imagery to support problem solving</li> </ul>	<ul style="list-style-type: none"> <li>• Frequently misplaces objects or forgets to turn in assignments; appears disorganized</li> <li>• Stands too close to classmates in line; difficulties judging personal boundaries</li> <li>• Difficulties with finding a position when playing a team sport in Physical Education</li> <li>• Problems remembering the locations of the classrooms when changing classes</li> <li>• Struggles to remember the class schedule, the order of routines, or the steps to tasks</li> <li>• Difficulties copying information from the board due to visual distractions from extraneous material or decorations</li> <li>• Difficulties planning the layout of work on a page. For example, starts writing in the center of page instead of on the upper, left-hand line.</li> <li>• Misses relevant information presented near the edges of a page in a text. Poor scanning abilities.</li> </ul>
<b>Gross and/or Fine Motor Skills</b> [28,49]	<ul style="list-style-type: none"> <li>• Poor hand-eye coordination</li> <li>• Appear clumsy</li> <li>• Difficulties with visual-motor integration</li> <li>• Poor graphomotor skills (handwriting)</li> <li>• Poor fine motor skills</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties with skills such as cutting with scissors, coloring, or sewing</li> <li>• Difficulties tying shoes</li> <li>• Poor letter formation and slow rate of writing speed</li> <li>• Difficulties completing tasks that require the hand to be guided by visual stimuli such as artwork and/or crafts</li> <li>• Difficulties with hitting and/or catching a ball</li> </ul>
<b>Self-regulation</b> [50-52]	<ul style="list-style-type: none"> <li>• Difficulties adjusting responses to the environment or setting</li> <li>• Inconsistent ability to attend to stimuli on cue</li> <li>• Inability to control or shift physical and/or emotional responses as the setting changes</li> <li>• Poor energy modulation, such as having difficulties with calming when needed to prepare to complete a quiet task</li> <li>• Poor internal sense of time</li> <li>• Unaware of their actions on others</li> </ul>	<ul style="list-style-type: none"> <li>• Cannot sit still in class</li> <li>• Easily startled</li> <li>• Runs in the hall and/or into the classroom when entering from an outside activity or recess</li> <li>• Difficulties controlling vocal intonations, may talk too loud for indoors</li> <li>• Problems stopping an action when asked by an instructor or a peer</li> <li>• Appears defiant when asked to shift to a calm state</li> <li>• Works in spurts and requires frequent adult assistance to complete task</li> </ul>

## Improving Outcomes in Adolescents and Adults with Fetal Alcohol Spectrum Disorders

Mary DeJoseph \*

New Jersey/ Northeast FASD Education and Research Center, University of Medicine and Dentistry of NJ, Newark, NJ, USA

*“Fetal Alcohol Syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood....” Ann Streissguth, JAMA 1991*

*“I remember when I finished high school, everyone was talking about where they were going and what they were doing next. I spent all of high school trying to survive every day. I didn’t think about planning ahead. At my graduation, I suddenly thought ‘Oh my God, what do I do now?’” (Fran, an adult with FAS)*

**Abstract:** Fetal Alcohol Spectrum Disorders (FASD) are life long and do not disappear with maturity. As children who have been exposed prenatally reach pubescence, they will experience the typical physical and emotional issues associated with adolescence. Navigating the rocky waters of adolescence is particularly challenging to individuals whose developmental abilities are significantly less than what is expected of them according to their chronological age. In many instances, physical, psychological, behavioral and social problems become more serious and continue on into adulthood for those with FASD. Lifespan issues considered in this chapter are: routine health care; safety; sleep; oral and dental care; nutrition and fitness; sexuality; sexual abuse; work; and co-occurring disorders. Practical considerations are also suggested.

### ADOLESCENCE: THE AGE OF ANGST

Progressing through the stages of adolescence into adulthood is challenging, even in the typically developing teen. Development is expected to include the achievement of predictable physical, mental, social, and behavioral milestones. While adolescence is generally considered to extend from 12 to 18 years, this range is not well defined as the onset of pubescence and the associated developmental stages may begin earlier and continue on into the early twenties. In addition, societal perceptions of when adolescence ends and adulthood begins, varies greatly. For example, several legal processes must be initiated by age 18. These include partial or complete guardianship and informed consent for medical treatment. Other rights, however, are not bestowed until the age of 21 (See Chapter 7).

During typical adolescence, teen-agers are expected to develop and master a broad range of abilities prior to entering adulthood. These include:

- comprehending abstract content such as higher order mathematics and moral and ethical standards, including rights and privileges;
- establishing and maintain satisfying personal relationships;
- moving gradually toward a more mature identity, purpose and independence;
- developing self-direction and pursue career interests;
- identifying more with peers than with parents.

The sudden and rapid physical changes that both genders experience during adolescence make this period one of extreme social awkwardness, self-consciousness and sensitivity. Simultaneously, rebellion, opposition and conflict with parents are appropriate developmental behaviors [1]. The amount and intensity of conflict that arises between

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\*Address correspondence to Mary DeJoseph: New Jersey/ Northeast FASD Education and Research Center, University of Medicine and Dentistry of NJ, Newark, NJ, USA; E-mail: marydejo@comcast.net

teen-agers and their parents is dependent to an extent on the support and stability of the childrearing environment [2]. Risk taking and exploration are behaviors associated with normal adolescent development [3]. Because good decision making skills generally lag behind physical size, strength and agility, safety and injury prevention are constant concerns in all adolescents. Information on injury, violence, poison prevention and other “critical adolescent health issues”, from the American Academy of Pediatrics can be accessed at: <http://www.aap.org/sections/adolescenthealth/criticalissues.cfm>. One source for a review of developmental milestones in adolescence can be found at: <http://www.nlm.nih.gov/medlineplus/ency/article/002003.htm>

Adolescence presents difficult challenges for individuals with an FASD. Normal, hormonal-driven sexual and physiological changes will occur within the appropriate growth period while the person with an FASD will continue to function at much younger, intellectual, social and behavioral stages than that expected of their chronological age. As a result, developmental milestones may be delayed indefinitely or missed altogether. Some isolated maturation milestones might be achieved, but it is difficult to predict which will be achieved, which will be delayed, and which milestones will never be reached. Not equipped with the necessary developmental skills leaves persons with FASD incapable of navigating the complex world. Compounding this situation is that educational and many social support systems end when the individual with FASD reaches age 18 or 21, and then leaves the school system.

The biological processes inherent in adolescence do not stop the long term effects of prenatal exposure to alcohol. Although teens with FASD will experience growth spurts, postnatal growth retardation is likely to result in short physical stature. While neurological development continues into early adulthood, the amount of actual brain growth in persons with FASD will be affected [4]. As discussed in Chapter 3, the secondary disabilities associated with FASD become more pronounced [5]. Behaviors that may have been ignored, tolerated or enabled at earlier ages may now escalate to become dangerous and criminal. Cumulative stress from traumatic childhood experiences and primary brain damage increase the vulnerability of persons with FASD to develop significant co-occurring and psychosocial issues. [6-8]. Unfortunately, the point at which services are most needed to diagnose, intervene with and manage this population is exactly when services become most limited. Adolescents and adults may not have as distinct dysmorphia and growth deficits; the lack of diagnostic precision makes screening for FAS in adolescents, developmentally disabled adults, and institutional settings very difficult [9]. Without diagnosis, appropriate care teams cannot be organized. Clearly, decades of scientific research, as well as family and professional experience, demonstrate that the path to adulthood for a person with an FASD may be more difficult, convoluted, and perilous than in the typical person. There are many issues to be attended to for professional and personal care givers of the adolescent and adult with an FASD. One which has particular importance to long-term health, success, and quality of life is routine health care and preventive clinical services.

## **ROUTINE HEALTH CARE**

Although there may be many immediate behavioral, mental, and emotional issues and/crises to deal on a daily basis, routine medical and dental care for the adolescent or adult with an FASD should not be ignored. This includes recommended history, physical exam, labs, and immunizations. Health care providers (primary care or specialists) who are also willing to deal with multiple, complex issues must be found and often educated. Concerns specific to the FASD must also be monitored and addressed. Some pediatricians may be willing to extend care with long-term patients, even into adulthood. This must be addressed with the individual pediatrician. Long-term care for adults and then geriatric care will have to be found and transitioned into.

The American Academy of Pediatrics (AAP) Council on Child and Adolescent Health has a statement on the age limits of pediatrics: “The purview of pediatrics includes the physical and psychosocial growth, development, and health of the individual. This commitment begins prior to birth when conception is apparent and continues throughout infancy, childhood, adolescence, and early adulthood, when the growth and developmental processes are generally completed. The responsibility of pediatrics may therefore begin with the fetus and continue through 21 years of age. There are special circumstances (eg, a chronic illness and/or disability) in which, if mutually agreeable to the pediatrician, the patient, and when appropriate the patient's family, the services of the pediatrician may continue to be the optimal source of health care past the age of 21 years.” Online access to this statement can be found at: <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;81/5/736>

Recommendations for major preventive clinical services throughout adolescence and adulthood have been published by the United States Preventive Services Task Force (USPSTF), American Medical Association (AMA), American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), Healthy People 2010. The recommendations are similar; any one may serve as a guideline for a parent to check or clinician to use to organize history, physical, labs, and immunizations. A checklist for prevention materials and health maintenance guidelines for consumers/patients at any age is found at <http://www.ahrq.gov/clinic/ppipix.htm>. The specific checklist for women, for example, is found at: <http://www.ahrq.gov/ppip/healthywom.htm>. The Department of Health and Human Services, Office of Disease Prevention and Health Promotion provides access to multiple other nutrition and fitness resources. This link can be found at: <http://odphp.osophs.dhhs.gov/>

Although dated, a still useful comparison of adolescent recommendations [10] has been adapted and is available in the adolescent health curriculum from the USC Keck School of Medicine. This link can be found at: [http://www.usc.edu/student-affairs/Health\\_Center/adolhealth/content/a8.html](http://www.usc.edu/student-affairs/Health_Center/adolhealth/content/a8.html)

An expanded listing of national and international recommendations can be found at the links at the end of the chapter resources.

Adults with developmental disabilities in general may have significant health challenges and experience poorer health because of social circumstances, genetics, environment, individual behaviors, finances, nutrition, and health care access [11]. They may have multiple prenatal and postnatal exposures to environmental toxicants, which interact with individual genetic susceptibilities [12,13]. Comparative studies concerning people with intellectual disabilities have found a higher prevalence rate for epilepsy, diseases of the skin, sensory loss, and increased risk of fractures [14]. Women with a disability have a higher rate of some conditions, such as depression after trauma, when compared to men with the same disability or women with the trauma and no disability [15]. Depression impairs motivation in treatment and wound healing [16]. The life expectancy of people with mild intellectual disability does not differ from the general population. People with mild and moderate intellectual disabilities have longer life expectancy than 35 years ago; this presents a challenge to primary care and geriatric health care providers. People with profound disabilities continue to have shorter life expectancy [17].

Adolescents and adults with an FASD have additional health concerns. Diagnosis or continued monitoring of alcohol - related birth defects (ARBDs) is an ongoing health consideration. Growth deficiency that was initiated in utero with a combination of alcohol use and maternal undernutrition may persist into adulthood [17]. Marginal maternal deficiencies in nutrients like zinc may exacerbate alcohol related damage and lead to long-term problems in the offspring via epigenetic factors. Marginal zinc and iron deficiency may persist in the adolescent or adult with an FASD, despite an adequate diet postnatally [18]. Prenatal exposure to alcohol has detrimental effects on the developing immune system, immunocompetence [19], and the immunosuppressive effects of stress; adults and adolescents and adults with FASDs will need more frequent attention to infectious disease [20]. Some infectious diseases may increase in severity with an immune system that has been prenatally exposed to alcohol [21]. Alcohol also affects the developing hypothalamic-pituitary axis (HPA); alcohol can increase HPA tone in both mother and offspring. This leads to increased exposure to exogenous glucocorticoids and life-long impaired stress management [22]. Auto-immune diseases that are exacerbated by stress may be an increased concern. Research with adolescents and adults with FASDs on health risks specific to this disability needs to be done.

## **SAFETY**

Safety is another primary health issue for adolescents and adults with FASDs. This population has a number of risk factors for accidents and injury: poor decision making; impulsivity; impaired motor co-ordination, working memory, attention, emotional and sensory regulation; and susceptibility to peer pressure. Even seemingly routine tasks like crossing the street safely may be impossible for those who are more severely affected.

One safety issue to highlight is driving. Many adolescents and adults with an FASD are able to complete requirements to get a driver's license and are consistently responsible and safe drivers. For others, driving safety may be adequate during routine driving and testing, but compromised under stress by impaired executive functioning and working memory, slowed problem solving, visual spatial deficits, and altered oculomotor control

## Fetal Alcohol Spectrum Disorders and the Law

**Kathryn A. Kelly\***

*Project Director, FASD Legal Issues Resource Center, Fetal Alcohol and Drug Unit Department of Psychiatry and Behavioral Sciences, School of Medicine, University of Washington, USA*

***“We can envision few things more certainly beyond one’s control than the drinking habits of a parent prior to one’s birth”***

**Florida Supreme Court *Dillbeck v. State* (1994)**

**643 So. 2d 1027, 1029**

**Abstract:** Legal standards and legal institutions have a great impact on the lives of individuals with Fetal Alcohol Spectrum Disorders (FASD). Most individuals with FASD need and are eligible for a range of special services and programs. Frequently, however, it is difficult to obtain that assistance because the application processes are complex and because program officials are not familiar with FASD. The programs and services of particular importance include an appropriate education, Social Security benefits, and state programs for individuals with developmental disabilities. Approximately 60 % of individuals with FASD get in trouble with the law. Officials in the criminal justice system rarely recognize or understand FASD, and the system often treats defendants with this disability in a manner that is ineffective. Parents of and advocates for individuals with FASD need to better understand how to deal with the criminal justice system, and officials in that system need to be trained about FASD and about more appropriate corrective and other legal responses.

### INTRODUCTION

Law, legal standards and legal institutions are of central importance to individuals with Fetal Alcohol Spectrum Disorders (FASD). First, for much of their lives most of these individuals will be dependent, often increasingly so, on a range of government services and programs. Because FASD cannot be treated medically—the underlying organic brain damage cannot be repaired—the quality of life of these individuals depends to a substantial degree on how society, particularly government agencies and programs, treat them. Obtaining access to needed services and programs requires understanding and meeting the legal rules that govern eligibility, as well as becoming familiar with the legal procedures and obstacles that stand in the way. As one parent of a child with FASD poignantly noted, no one who needed these services could possibly master the application process. Also, at some point in their lives, most of those with FASD are going to get in trouble with the law. When they do, legal standards and procedures establish the framework for deciding whether they will get assistance from the courts, will be punished (and if so, how severely), or will simply end up back on the streets [1-3].

These issues, and the importance of the law, are likely to increase as an individual with FASD grows from infancy to adulthood. When children with FASD are young, parents may be able, and might even be in the best position, to help deal with the behavioral problems associated with FASD. But as the children grow older, the ability of parents to deal with these problems will often decline. The problems of adolescents and adult children often cannot be solved by their parents. Parents may find older children harder to deal with, and, as their offspring age, the capacity of parents to intercede on their behalf will be reduced. Also, at some point parents have to worry about how these sons and daughters will function when the parents can no longer be active in their lives.

Individuals with FASD usually fare poorly when they have come into contact with the law. Legal rules, standards and procedures were not written to deal with FASD as such. The officials involved in the administration of those rules, standards and procedures—agency officials, lawyers, judges, and others—often are unfamiliar with FASD and have no idea when an individual might have that disability. The overarching task for parents, advocates, and

\*Address correspondence to Kathryn A. Kelly: Fetal Alcohol and Drug Unit, 180 Nickerson Street, Suite 309, Seattle, Washington, 98109, USA; E-mail: faslaw@u.washington.edu

attorneys representing individuals with FASD is to bridge this gap. They must learn and articulate how the behavioral patterns of individuals with FASD can be seen to fit appropriately into the relevant legal structure and standards. At times this means that parents who understand the problems of their son or daughter, but not why the government or attorneys are being unhelpful, must somehow communicate with officials and attorneys who understand the law but are frustrated with the behavior of that son or daughter and his or her inexplicably overprotective parents.

At times, the same event may look entirely different to parents or advocates on the one hand, and to judges, lawyers and agency officials on the other. For example, an individual with FASD who is on probation may frequently fail to keep appointments with a probation official. The probation officer will probably see that problem as indicating the need for punitive action in order to teach the probationer the responsibility to keep appointments and the adverse consequences of failing to do so. A parent, on the other hand, would be likely to see that behavior as the inability of the individual with FASD to remember appointments and to manage and keep track of time. What seems an attitude problem to the probation official would be a symptom of the disability to the parent.

The problems that arise from the interplay of FASD and the law are numerous and complex. There is, however, one step useful in almost all these arenas: obtaining a medical diagnosis of FASD. To those involved in the administration of the law, there often will seem to be nothing terribly wrong with an individual with FASD, no problem to which the law should, or even could, respond. A medical diagnosis—even if its exact meaning may not be clear—can be uniquely effective in persuading agencies and courts, lawyers and bureaucrats that there is more to the situation before them than meets the eye.

A variety of useful materials in relation to obtaining a diagnosis can be found at the Web site of the Fetal Alcohol Unit of the University of Washington: <http://depts.washington.edu/fadu/legalissues/> and at the Web site of FASD Ontario Justice Committee: <http://fasdjustice.on.ca/>

## **ELIGIBILITY FOR SOCIAL PROGRAMS**

Most individuals with FASD need—although they may not receive—special services and assistance to cope with their disability. The relevant programs, such as the state agencies for the developmentally disabled or Social Security benefits do not ordinarily provide automatic eligibility to those with FASD; indeed, in many instances the existence of FASD as such may not be relevant. To obtain the needed services and assistance it must be demonstrated that the symptoms and manifestations of that disability fall within the particular standards utilized for the program in question. Understanding the eligibility rules and mastering the procedures of each agency for establishing eligibility are of critical importance. Agencies can be quite idiosyncratic in their requirements regarding the information and documents to be provided or the tests to be administered; what matters is not what might be convincing to a parent or advocate, but the established agency method of proceeding. The burden of doing so is usually the responsibility of the individual, the family or an advocate seeking admission to the program in question; precisely because of the disabling effect of FASD, the burden of meeting these standards and navigating those procedures falls on family members or other advocates. As the father of one individual affected by FASD reflected “No one who needs these services could possibly apply for them”.

Frequently the documents needed to begin an application process—application forms, instructions, standards, lists of needed supporting material—can be found on the Web site of the agency in question.

## **Individuals with Disabilities Education Act**

The Individuals with Disabilities Education Act (IDEA) requires that public schools provide for any student with a disability an Individualized Education Program (IEP) tailored to the specific needs of the student. Most schools and school districts are familiar with this requirement and have a range of approaches for dealing with this legal obligation.

Many teachers and schools, however, are unfamiliar with the particular needs of students with FASD and with the specific teaching techniques that are likely to be effective for those students. There is a substantial amount of material about those needs and techniques, and it may be helpful for parents or advocates to identify or provide those materials to the school officials responsible for preparing the IEP. The federal government supports an office



that provides useful information about FASD, the SAMHSA (Substance Abuse Mental Health Services Administration) FASD Center for Excellence. Materials at that office's Web site dealing with education problems can be accessed at: <http://www.fasdcenter.samhsa.gov/grabGo/factSheets.cfm>

Education officials at the Yukon Department of Education in Whitehorse, Canada have developed a detailed teaching curriculum for students with FASD, which can be accessed at the Web site of FASD Connections: <http://www.fasdconnections.ca/ieh2.htm>

### **Social Security**

The Social Security Administration administers several assistance programs for which individuals with FASD may be eligible.

Supplemental Security Income (SSI) are financial benefits for adults whose disabilities are so severe that they cannot work full time and who do not have substantial other income or financial assets. To be eligible an applicant must be unable to work full time at any job, not merely unable to work full time at his or her past or preferred job. There is an exception for individuals who work full time in special job programs for individuals with disabilities. To establish eligibility an applicant must be able to show both that he or she has a disability and that the disability is the reason he or she cannot work full time. The Social Security Administration (SSA) recognizes that FASD is a disability, and that it is a disability that can prevent an individual from working full time. It is not enough, however, merely to show that an applicant has FASD; there must also be a demonstration of the effect of the disability on the applicant's ability to work. Under certain circumstances an individual can continue to receive SSI benefits even though he or she is working; the rules governing whether an individual can do so are set out on the SSA Web site: <http://www.socialsecurity.gov/pubs/10095.pdf>

SSA also provides assistance for children with disabilities if their disabilities cause "marked and severe limitations" and the parent or parents of the child have very limited income and assets.

Additional information about these programs can be obtained by calling the Social Security Administration's toll free line, 1-800-772-1213. Much information is also available on line at <http://www.ssa.gov>

The process of applying for either of these programs involves submitting a detailed application. If an initial application is denied, the applicant can seek review of that decision, and is entitled to a hearing [2]. The process of working through this system is described at the Social Security Administration Web site, and in the article available at: <http://depts.washington.edu/fadu/legalissues/>

An attorney is not required to handle the initial stages of this application process, although one may be helpful. Pursuing a legal appeal of a denial of benefits usually does require a lawyer. There is a national organization of attorneys and others who represent individuals applying for Social Security benefits, the National Organization of Social Security Claimants Representatives (NOSSCR). That organization's Web site can be accessed at: <http://www.nosser.org/>

It is possible to arrange for Social Security benefits to be paid to a designated third-party payee. That may be an important safeguard for the individual with FASD who has difficulty handling money.

### **State Developmental Disabilities Programs**

All states have some program to assist individuals with developmental disabilities (DD). The nature of those DD programs vary widely. Some are limited to assisting clients in obtaining access to the programs of other agencies, federal, state, local or even private. Other DD programs provide services, housing, a permanent counselor or advocate, or financial assistance to individuals. An official of a DD agency, for example, might be a designated payee for a client receiving Social Security. In general, any and all of these types of programs can be of considerable value to individuals with FASD [3].

The eligibility standards for state DD programs also vary greatly from state to state. Most of these programs were originally limited to individuals with a full scale IQ score of 70 or less, and were expressly denoted as programs for



## Families Living with FASD: Up Close and Personal

Kathleen T. Mitchell<sup>1,\*</sup> and Mary DeJoseph<sup>2</sup>

<sup>1</sup>National Organization on Fetal Alcohol Syndrome 1200 Eton Court, NW, Third Floor, Washington, DC 20007; USA and <sup>2</sup>UMDNJ-NJMS, New Jersey FASD Education and Research Center, Newark, NJ

*“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it’s the only thing that ever has”*

Margaret Mead

**Abstract:** This chapter contains a series of unedited stories from family members and people affected by prenatal alcohol exposure. There is an entire spectrum of family needs, just as there is a spectrum of effects. All families share the grief of lost dreams for their children and the shocking transition to a whole new journey in parenting. All families are stretched beyond expectation emotionally, mentally, spiritually, and financially. Health, marital, and safety challenges are common. The chapter includes contributions from both adoptive and birth families, mothers and a father, affected people and siblings, with and without alcoholism in the family.

### INTRODUCTION

Raising a child with Fetal Alcohol Spectrum Disorders (FASD) can be both challenging and rewarding. Today, there are FASD family support groups scattered across the United States and on-line. Many states have trained FASD Coordinators and diagnostic centers. The National Organization on Fetal Alcohol Syndrome (NOFAS) and other agencies provide information, support, and advocacy to families, healthcare professionals, educators and policy makers. There is an abundance of materials and information available for both parents and public health agencies (See suggested readings at the end of this chapter). Family centered care should remain at the heart of diagnosis, management and follow-up for affected individuals and their families.

Receiving a diagnosis of an FASD is never easy for families. Adoptive families may have a different response than birth families do. Adoptive or foster parents may experience anger as their first emotion. Their anger is often towards the birth mother initially. Later they may direct their anger towards the adoption or foster care agency for the lack of disclosure. Birth families, however, experience initial shame and remorse. Recognizing that your child lives with a disability because you drank during pregnancy is a sad realization that often is compounded by late diagnosis for the child. The diagnosis of an FASD will likely trigger a period of grief for all families, both adoptive and birth. Forgiveness is an important step in healing and moving forward.

Both alcoholism and FASD remain highly stigmatized disorders. Being a birth mother is like being branded with a *Scarlet Letter (I’m a Bad Mother)* that both she and her family must carry for the rest of their lives. Long after recovery from alcoholism, mothers and their families face continuing shame and stigma from neighbors, children’s teachers and friends, extended family members, physicians, etc. Stigma is a major issue and causes problems on many levels. Faced with the prospect of stigma, women who drink during pregnancy may deny they have a problem and be reluctant to pursue a diagnosis. Some physicians are reluctant to diagnose an FASD because of the labeling and stigma that ensues for mothers and children. Stigma and shame can lead to relapse, escalation in drinking, and medical complications.

**One does not have to be an alcoholic to give birth to a child with effects from drinking while pregnant**, but it is clearly understood that women with addictive disorders, such as alcoholism, are the highest risk group for having children with an FASD. Alcoholism should be viewed as a progressive disease and should be diagnosed and treated

\*Address correspondence to Kathleen T. Mitchell: National Organization on Fetal Alcohol Syndrome 1200 Eton Court, NW, Third Floor, Washington, DC 20007, USA; E-mail: Mitchell@nofas.org

within a disease management and recovery model, but must consider general societal attitudes and beliefs towards drinking. This would reduce stigma and thereby increase the likelihood of preventing FASD. Many addicts have themselves been exposed to alcohol prenatally; identification of these adults in our systems of care could result in a reduction in recidivism and obtaining appropriate support and services. Whether or not alcohol is identified as the mother's primary substance of abuse, assessment and screening should include asking questions about amounts and frequency of alcohol use, and should explore the possibility of prenatal alcohol exposure in the adult client and her pregnancies. Knowing that an adult client has been exposed to alcohol prenatally, or who may have prenatally exposed their children to alcohol would be important information to make appropriate referrals and to the on-going treatment planning process. Comprehensive, long-term case management for both the mother, effected child (ren), and other family members should be considered [1,2]. A platform that includes research and implementation is needed to inform the broader health care and educational system about addiction and FASD [3-5].

To address the issues of stigma, trauma and to support birth families, the NOFAS Circle of Hope (COH) was formed in 2004 and in 2005 the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence funded NOFAS to support the Circle of Hope-Birth Mothers Network (COH-BMN). The COH-BMN is an international FASD birth mom peer mentoring network. There are regional COH-BMN coordinators located throughout the United States. The coordinators are available to connect with and support birth mothers who have used alcohol during pregnancy and/or have a child (ren) with FASD. Its mission is "to increase understanding and support and strengthen recovery for women who drank during their pregnancy(s), and their families." The goals are to improve and strengthen the lives of birth families, provide peer support for birth families, and decrease the stigma, blame, and shame that birth families may experience. The COH-BMN accomplishes its mission and goals by educating agencies that serve high-risk women, educating policymakers and agency directors. The COH-BMN speakers' bureau provides trained speakers who are available to provide personal testimony and training on FASD. All of these activities support the values guiding the network which are confidentiality, honesty and integrity of all members, reducing the stigma of FASD, and assuring a safe environment for women. The COH-BMN seeks to create momentum and cohesiveness for national action to prevent FASD. To contact the Circle of Hope Birth Mothers Network (COH-BMN) go to <http://www.nofas.org/coh/default.aspx>

## **HERE ARE OUR STOIRES**

### **A Survivor from the Beginning: An Adult's Story of Living With Fetal Alcohol Syndrome**

I'm 50 years old and I live in Fort Lee, New Jersey. I've rented a room in the home of an 87 year old woman who is an angel. She's like a grandma to me. I've lived there for about 7 years and we have really gotten to love each other; I'm there for her and she's there for me. Her age is really starting to catch up with her- she's had some serious falls. Now I do all the food shopping, driving, giving her medicine and calling to remind her when to take it.

I work at a CVS as a cashier and it is really hard and overwhelming for me. I work 35 hours a week so I can keep my benefits. I've moved from a bigger store to a smaller one and I hope it helps, because I'm not sure how much longer I can hang in there. Some days I don't want to do it anymore, but I don't have a choice. Maybe I could qualify for disability, but I don't know how to do that.

I am one of 4 children- mom had the first three a year apart, then 7 years later she had me. She was 31 years old when she had me. I've gotten bits and pieces of the story- her alcoholism got much worse during the 7 years before she had me. She definitely drank while she was pregnant with me. My brother and sisters are fine. The FAS made me different. I was born tiny and premature. My doctors and family thought I wasn't going to make it. I guess I was a survivor from the very start! I watched my mom turn to skin and bones, drinking all the time and too drunk to get out of bed. Her alcoholism was our big family secret. She died when I was 11 and she was 42.

My mom was never really involved with me. My sister raised me. I remember another angel in my life: my brother's wife. She always included me in their family when I was growing up. She shared her home, her new baby, and her weekends with me. She taught me how to drive and took me on summer vacations. She died of cancer when she was only 29 years old.

School was very hard for me; I remember thinking how hard I had to focus all the time. I didn't have any friends; it was very lonely. I still tend to isolate. My worst subjects were math and history. Even today at work, if there is any counting to do, I have to use a calculator. I can't get a pharmacy certification, because there's a lot of math on the test and the pressure is too overwhelming.

I remember when I finished high school everyone was talking about where they were going and what they were doing next. I didn't have all those plans. I spent all of high school trying to survive every day. I didn't think about planning ahead. At my graduation, I suddenly thought "Oh my God, what do I do now?" My family wanted me to go to business school so of course I did what they expected of me. They had high expectations of me. I was terrified of disappointing them. I went to a business college in Manhattan for about half a year. Then I realized it couldn't work and I walked out. I still got up every day and left the house and pretended as if I were going to school. Then I just walked around or sat somewhere all day. They found out and I got my first job.

I've always had trouble with keeping jobs, but I had that first job for 6 yrs. A good friend of my dad's hired me as a file clerk at an insurance company. It was good until they started promoting me. When they made me a typist, I hit another wall because I couldn't spell and there was a lot of pressure. I quit before I was fired.

When my father retired, he was planning on remarrying and moving to the Catskills. He said I could stay on at our home and try to make it on my own. I had grown up most of my life in Washington Heights, Manhattan; I figured I could stay and rent out some rooms and take care of myself. Some really weird and scary people stayed with me. One was even in my room in the middle of the night. I figured that was enough of that.

My brother invited me to come and stay with him in New Jersey and find a job. I lived there for a couple years and found some jobs here and there in retail and a drug store. A lot of people helped me with jobs, but I didn't really know what I wanted, and I had no idea about the FAS. I just knew something was different, something was wrong with me. At this point, I started to drink. I really wanted to die, but I was afraid to die. At this point, I got help and started to see a therapist. Slowly and gently she helped me to realize that I am from an alcoholic family. I got clear that my mom drank while she was pregnant. I stopped drinking and have been going to the 12 Step program Al-Anon for 17 years. I go to 3 meetings a week and retreat twice a year. I love it there and have lots of friends.

After that, I lived with my sister and her husband. When they were getting ready to move, I couldn't move with them. I thought maybe getting a medical diagnosis of FAS would help me get some support. I made a lot of phone calls and talked to (Dr.) Ann Wilson at The Arc of New Jersey. I went for all the FAS testing at Dr. Susan's clinic (the Northern NJ FAS Diagnostic Center at UMDNJ-New Jersey Medical School); she is another angel who is always there for me. The testing was really hard, but she helped me through it and made me feel comfortable and told me I could stop if it was too much.

Along with FAS, I have Osteogenesis Imperfecta (OI). I always had soft bones and a lot of broken bones. In my early 30's, I had back pain and hearing loss and osteoporosis. A doctor finally noticed that I had blue sclera and told me I have OI. I am in a support group for OI- it is a small group, but every month we get together for a meeting or a picnic. I am the only one in the group who drives and is mobile, I have a mild case. This gives me a whole network of friends. I also struggle with an eating disorder and with anxiety and depression. The medicine helps but it has to be changed a lot.

For fun, I like to do yard work and gardening. It is very calming to be outside. I love animals- I walk dogs and take care of cats for neighbors when they call me. It is my dream to be a service or companion dog trainer, but that's not in the picture right now.

Here's what I would tell others with FAS: There is hope and help out there. I wouldn't have survived if I didn't fight for myself, even with all the shame and embarrassment. If your family is not supportive, go to friends who are. I look for people who accept and love me for who I am.

-Reviewed and submitted by Fran (dictated to Mary D)

## Translating Research into Action: Federal and State Initiatives

Deborah E. Cohen<sup>1</sup> and Susan A. Adubato<sup>2,\*</sup>

<sup>1</sup>New Jersey Department of Human Services, Division of Developmental Disabilities, Hamilton, NJ and <sup>2</sup>University of Medicine and Dentistry – New Jersey Medical School, New Jersey FASD Education and Research Center, Newark, New Jersey, USA

*“For persons with developmental disabilities and their families, diagnosis is never an endpoint ”*

National Task Force on FAS/FAE, 2002

**Abstract:** Basic research into Fetal Alcohol Spectrum Disorders (FASD) is contributing much important information to our understanding of the dynamics of how alcohol affects developing neurological and physiological systems in unborn children. Clinical research is beginning to offer guidelines for intervention, treatment and services for women who may abuse alcohol and to children who are affected by prenatal exposures. It is equally important that, when the findings of research reach the point of utility, they be put into practice as standards of care. While the types and availability of services vary among states, most jurisdictions do support systems that can provide services and treatment to these populations. The purpose of this chapter is fourfold: 1. Provide an overview of the work that has been undertaken by federal agencies and associated task forces to develop innovative interventions and to encourage and reinforce the implementation of services on the state level; 2. Describe the service components that are generally available in each state; 3. Provide a description of service models that have been established or are evolving on the state level; and 4. Describe the role of voluntary agencies in the non-profit sector in establishing service systems for persons with FASD.

### LEADERSHIP BY NATIONAL AGENCIES

Recognition that national governmental agencies needed to have open communication among them and to play a leadership role in research and prevention of FAS was acknowledged in the early 1990s. One of the earliest documents to address FAS, *Fetal Alcohol Syndrome and Pregnant Women Who Abuse Alcohol: An Overview of the Issue and the Federal Response*, was produced through interagency collaboration and published by the U.S. Department of Health and Human Services (USDHHS), Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy, Division of Children and Youth Policy in February 1992 [1]. Experts from the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Indian Health Service (IHS), the Centers for Disease Control (now “and Prevention”) (CDC), and the Administration for Children, Youth and Family (ACYF) participated in writing this document. It is noteworthy for bringing together representatives from several federal agencies that are responsible for addressing alcohol abuse in women and its impact upon fetal development as well as for the broad range of issues it raised. One chapter in particular, “Gaps in Knowledge and Services”, identified some components of a comprehensive service system and began the task of identifying the appropriate services needed by persons with FASD [1].

As described in previous chapters, the Institute of Medicine (IOM) published a report on FAS in 1996 that underscored the importance of a coordinated effort among federal agencies in addressing the myriad of issues associated with preventing and treating FASD [2]. One of the primary outcomes of the IOM report was the establishment of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) in October 1996 [3]. The IOM report noted that the responsibility for addressing the many issues relevant to FASD transcended the mission and resources of any single agency or program. It recommended that the NIAAA chair an effort to coordinate Federal activities on FAS and other disorders associated with prenatal alcohol exposure. As posited in its mission statement, “The challenge facing the ICCFAS is to improve communication, cooperation, and collaboration among disciplines that address health, education, developmental disability, research, justice, and social service issues relevant to FAS and related disorders caused by prenatal alcohol exposure” [3].

\*Address correspondence to Susan A. Adubato: UMDNJ-NJMS New Jersey FASD Education and Research Center 30 Bergen Street ADMN 1608 Newark, NJ 07101, USA; E-mail: adubatsu@umdnj.edu

Meeting semi-annually, the membership of the ICCFAS is broad-based and includes representatives from the following agencies:

**The Department of Health and Human Services (DHHS):**

- Agency for Healthcare Research and Quality (AHRQ);
- Centers for Disease Control and Prevention (CDC);
- Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau (MCHB);
- Indian Health Service (IHS);
- National Institutes of Health (NIH):
  - National Institute on Alcohol Abuse and Alcoholism (NIAAA) and
  - National Institute of Child Health and Human Development (NICHD);
- Substance Abuse and Mental Health Services Administration (SAMHSA);

**The Department of Education (ED):**

- Office of Special Education and Rehabilitative Services (OSERS); and

**The Department of Justice (DOJ):**

- Office of Juvenile Justice and Delinquency Prevention (OJJDP).

Early in their deliberations, members of the ICCFAS recognized that issues related to the behavior, social and health impacts of prenatal alcohol exposure were largely unknown and little research had been conducted in these areas. To learn more about these topics, the ICCFAS held a special focus session in September 1998 and published its proceedings, **Intervening with Children Affected by Prenatal Alcohol Exposure** [4]. These proceedings are one of the first documents to look more closely at specific state systems, e.g., mental health, developmental disabilities, special education, that are crucial to addressing the needs of persons with FASD.

The work of the ICCFAS continues. Its mission and accomplishments is summarized in its Progress Report and Five-Year Strategic Plan found at: (<http://www.niaaa.nih.gov/AboutNIAAA/Interagency/Pages/default.aspx>)

In the late 1990s, advocacy agencies began to work with the U.S. Congress on two important pieces of legislation. These efforts resulted in: 1) the establishment of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE) (the Task Force) and 2) the founding of SAMHSA's Center for Excellence in FASD (the Center).

**NATIONAL TASK FORCE ON FAS/FAE**

In 1998, the U. S. Congress was made aware of the significant problems and costs associated with prenatal consumption of alcohol. In response, the Public Health Service Act, Section 299G (42 U.S.C. Section 280f, as added by Public Law 105-392) directed the Secretary of the U.S. Department of Health and Human Services (DHHS) to establish the Task Force [5]. The mission of the Task Force was to 1) foster coordination among all governmental agencies, academic bodies, and community groups that conduct or support FAS or FAE research, programs, and surveillance; and 2) otherwise meet the needs of populations impacted by FAS and FAE [5 – MMWR – Task Force]. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) was charged with the responsibility of administering the Task Force. As described in its charter, the functions of the Task Force were to:

- Advise persons involved in federal, state, and local programs and research activities of FAS and FAE regarding such topics as FAS awareness and education for relevant service providers and the general public (including school-aged children and women at risk), medical diagnosis for affected persons and their families;
- Coordinate its efforts with the DHHS ICCFAS; and
- Report, on a biennial basis, to the DHHS Secretary and relevant committees of Congress on the current and planned activities of the participating agencies [5].

Early in its operation, the Task Force formed two working groups: the Research Working Group and the Services and Public Awareness Working Group. The purpose of the Work Group was to evaluate existing FAS and ARND research

and services and to make recommendations concerning actions needed to remedy deficiencies. Several of the recommendations posited by the Public Awareness Work Group spoke to the need to establish or improve services for persons with FASD at the state level. Recommendation 12, in particular, articulated this need by stating, “Develop a checklist of essential state services needed to prevent FAS and ARND, to treat persons with FAS and ARND and their families, and to better identify women at risk of having an alcohol-exposed pregnancy” [5]. (The complete list of all recommendations can be viewed at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5114a2.htm>)

While the adverse effects of prenatal exposure are known, children who have been subjected to alcohol are often not referred for diagnostic evaluation or do not receive a correct diagnosis because of the absence of guidelines for referral and uniformly accepted diagnostic criteria. In 2002, Congress directed CDC to 1) develop guidelines for diagnosing FAS and other negative birth outcomes resulting from prenatal exposure to alcohol, 2) incorporate these guidelines into curricula for medical and allied health students and practitioners, and 3) disseminate curricula concerning these guidelines to facilitate training of medical and allied health students and practitioners.

In response to the Congressional mandate, CDC established a scientific working group (SWG) that consisted of persons with expertise in research and clinical practice regarding prenatal exposure to alcohol to develop diagnostic guidelines for FAS. The SWG worked closely with the Task Force to develop the guidelines. Both the SWG and the Task Force recognized that reaching consensus on the diagnostic criteria could not be the only outcome of their work. As a result, the *Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome* goes beyond the primary Congressional mandate to include sections that address the implementation of:

- effective programs to educate women about the risks of consuming alcohol during pregnancy.
- efficacious screening tools to identify pregnant women who are consuming alcohol during pregnancy and use of brief interventions.
- effective programs to encourage the use of contraceptives by women who abuse alcohol [6].

The Guidelines also contributed to the growing body of knowledge regarding the educational and service needs of persons affected by prenatal exposure to alcohol and their families. The Guidelines can be accessed at: <http://cdc.gov/ncbddd/fasd/documents/RedAlcohPreg.pdf>

<sup>§</sup>Following the issuing of the Guidelines, the Task Force and CDC concentrated on identifying and supporting scientifically proven programs that reduced the consumption of alcohol among women, establishing the efficacy of screening and implementation of brief interventions for pregnant women. In its deliberations, the Task Force noted the importance of several societal variables:

### Accessibility of Alcohol

Alcohol is a highly accessible and commonly consumed product that is integrated into many aspects of American culture, from special events to everyday life. However, it is one of the few socially acceptable products that is a major known contributor to disease, disability, and premature mortality [7]. Alcohol is a leading cause of morbidity and mortality in the United States [8,9]. Also, according to *Healthy People 2010* [10], substance abuse, which includes alcohol and illicit drug use, has been identified as 1 of the 10 leading health concerns that should be addressed and monitored to measure the health of the U.S. general population. Moreover, among all substances of abuse, alcohol is the one most commonly consumed by women of childbearing age [11].

### Reducing Alcohol-Exposed Pregnancies

The consumption of alcohol is pervasive in American society. SAMHSA’s 2007 National Survey on Drug Use and Health documents that over 50% of all Americans report that they consume alcohol. While one 10-year national trend study of alcohol consumption during the period 1984–1995 [12] noted an overall decline in drinking rates during the study period, virtually no changes were found during the period 1990–1995, prompting the author to question whether or not the period of declining drinking rates might be over.

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<sup>§</sup>This section was written by R. Louise Floyd, RN, DSN and Mary Kate Weber, MPH, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Prevention Research Branch, Fetal Alcohol Syndrome Prevention Team, Atlanta, GA and Mary J. O’Connor, PhD, ABPP, University of California at Los Angeles, Department of Psychiatry and Biobehavioral Sciences, David Geffen School of Medicine, Los Angeles, CA

## AFTERWORD

### Some Thoughts from a Doting Aunt:

#### Never, Never Underestimate the Power of Neurological Development,

#### Love and, Perhaps, Good Nutrition

Matt arrived when he was six weeks old. As an only child, an only grandchild and an only nephew, this infant was a gift to my family. At his first post partum visit a few weeks later, Matt's pediatrician pronounced him to be a perfect and healthy little boy. This was 1980, however, and even though Matt's face was already showing some of the dysmorphic features that would become more prominent over the next few months, most pediatricians had never heard of Fetal Alcohol Syndrome (FAS) at the time.

Our small family was fortunate for several reasons. First, because it was a semi-private adoption, my sister (mom) and brother-in-law (dad) were better informed about Matt's birth parents' backgrounds than is typical and, later when we needed it, were able to get some information about Matt's birth mother's behaviors during pregnancy. Thus, we knew that Matt's birth parents had been high school sweethearts who had gone off to college. Matt's birth mother got pregnant during the summer between her freshman and sophomore years, but, as happens too often, did not know she was pregnant when she returned to college. Matt's birth father was on the football team and his birth mother, it seems, partied hearty after every game. Once she realized she was with child, Matt's birth mother left school for the rest of the year, lived with an aunt, stopped drinking alcohol and received good prenatal care. While Matt was small at birth, he was within the normal ranges and his Apgar score was good. Matt's birth parents wanted to complete college and decided that the best course of action would be to put him up for adoption. We learned later that, after graduation, they had gotten married and had additional children.

The second fortunate circumstance is that Matt's adopted mom was a teacher who was greatly attuned to child developmental issues. While she suspected problems early on, Matt's delayed speech and language resulted in mom insisting that Matt be screened for developmental disorders at age three by his pediatrician. When the screenings showed clear delays, he recommended that Matt be assessed by a pediatric neurologist which led to our third fortuitous event. We all lived in the Boston area where there were a few pediatric neurologists who were familiar with the effects of prenatal exposure to alcohol and the telltale facial abnormalities. As a result, Matt received a diagnosis of FAS when he was still young. The neurologist predicted that Matt would have severe intellectual disabilities and would not be able to read, write or understand mathematics.

Matt's diagnosis was re-confirmed by another pediatric neurologist when he was five and preparing for his first Individual Education Plan (IEP) for Special Education (SPED). This time, however, Matt's intelligence tests showed that he was far from having "mental retardation" as his scores showed then, and have consistently done so ever since, an above average IQ. Aptitude and behavioral tests, however, have drawn a different picture, reflecting difficulties in abstract reasoning, memory and recall, language usage and comprehension, and other problems. Both his fine and gross motor skills were good and his mechanical abilities excellent.

The fourth area in which our family was fortunate pertains to Matt's education. Throughout his elementary and middle school years, Matt's mom was greatly involved with his school systems, first by operating an after school tutoring program and later by working as a permanent substitute teacher. As a result, mom got to know everyone involved in Matt's education and worked with them to ensure that her son got the academic attention he needed. Matt was never in separate special education classrooms, but was mainstreamed with time spent in Resource Rooms for additional help. Despite the initial prediction and while he did struggle mightily, Matt learned to read, write and perform arithmetic functions. However, he also experienced serious attention deficits, was unable to sit still as long as required and was often disruptive in the classroom. By Thursday night, he had it! Matt had reached the limits of his self-control and would have a melt down from the pressures of trying to learn, keep up with his peers, and behave appropriately within the social norms. Ritalin did help to contain these educational and behavioral issues, but finding the proper dosage was challenging and the medication needed to be altered frequently.

When he was nine years old, Matt and his parents moved from the Boston area to the southern Catskills in New York. Even the arrival of a promised puppy did not resolve the difficulties this change brought. Matt struggled to keep up in the classroom with cohorts who did not know or accept his learning problems. He found it challenging to make new friends and often got into trouble by trying to please them and be accepted by them.

Being of normal intelligence was both a blessing and a curse. It was a joy to realize that Matt could learn and have a future that was largely self-sufficient. However, as Matt struggled to fit into his new environment, he also became aware that he was somehow different than his peers were. He was old enough to recognize that learning came easily to most of his classmates while he wrestled to remember the lessons of the day; that none of them had trouble sitting still and attending to instructions; that none of his peers took medication; that most of them were larger than he was. The latter issue was particularly striking as Matt's postnatal growth retardation manifested itself completely during adolescence. Although Matt has always had a good appetite and enjoyed nutritious foods, including fresh vegetables and fruit, he has remained of short stature, even though both of his birth parents were tall. Matt began to act out more frequently, often expressing his frustrations, fears, and feelings of rejection and depression by telling lies, seeming to be conscience-less, throwing tantrums, and putting holes in walls with his fists. Matt's parents responded appropriately by investing in large amounts of spackle, hiring a good contractor and finding a psychiatrist to treat their son. It was impossible to locate a psychiatrist who was familiar with the psychological aspects of FAS, but, over the years, we have found that those who were trained to treat children with Attention Deficit and Hyperactivity Disorder (ADHD) were of benefit to Matt.

Matt reached the high point of his adolescence when he was thirteen. He decided that he wanted to give a present to his grandfather by participating in a complete Bar Mitzvah. For over a year, Matt memorized his Torah (Five Books of Moses) and Haftorah (Old Testament Prophets) portions in Hebrew by listening to audio tapes. He also learned all the blessings and wrote and presented a speech. Coincidentally and ironically, one of Matt's readings was from Judges 13:7 in which an angel tells Samson's future mother, "Behold, thou shall conceive and bear a son: And now, drink no wine or strong drink....". Many of Matt's friends from Boston came for the celebration and he has always said that "my Bar Mitzvah was the happiest day of my life." Unfortunately, after all the months of preparation for and excitement of the week-end, Matt crashed hard when it was over and severe depression set in. After experiencing several instances of rejection and anti-Semitism by peers, a school system that no longer met his educational needs and verbal abuse by an adult, his parents decided to send Matt to a private school that specialized in working with students with ADHD and other learning disabilities. The additional benefit was that the school was located in New Jersey near to where Matt's aunt lived. So, when Matt was fourteen, he started over again, or so his family believed.

As it turned out, Matt began to live the life described by Ann Streissguth in her 1996 study. He had shown signs of being attracted to cigarettes and alcohol at an early age. Unfortunately, the school Matt attended was not well-supervised and alcohol, tobacco and drugs were readily available. He was suspended several times for being in possession of these substances. Matt had a girlfriend two years his senior with whom he was engaged in an intense sexual relationship. He experienced clinical depression severe enough that his psychiatrist placed him on bed rest and medication for almost a month, during which he moved into his aunt's home. When he was well enough to return, Matt announced that he did not want to live at the school any longer and moved in with his aunt permanently. At the end of the year, Matt and the school administrators agreed that a parting of the ways would be best. However, Matt did not want to return to New York, so was enrolled in the public school where his aunt lived.

For the next year and half, Matt seemed to hold his own at the local school. He made friends, some of dubious distinction and influence. He found a nicer, new girlfriend and became involved in some after school activities. He did struggle with some of the class work, but the additional support from the Resource Room helped him to continue to learn and remain motivated. At the same time, Matt experienced periods of depression, confusion, belligerence, increased lying and secretiveness. Although Matt had known from an early age that he had been adopted, he seemed to blame his parents for his troubles and limited his interaction with them. This erratic behavior continued until the doorbell rang very early one morning in January, 1997. When his aunt answered the door, she found four police standing on her stoop with a warrant to arrest Matt for selling drugs.

One night in juvenile detention convinced Matt that this was not the future he sought. Matt's parents and aunt appeared in court the next day with the guarantee that this young man would be sent to a Substance Abuse



Treatment Center in New York. Matt completed his junior year in high school while at the center and returned to his original school system for his senior year. Thus, Matt lived the remaining characteristics described by Streissguth: involvement with the criminal justice system and interrupted schooling.

Matt performed well during his senior year in high school, particularly in his vocational education program, but remained depressed and an outsider. As the year was ending, it was clear that some plans were needed for post-graduation. Matt had always shown an interest in and a talent for cooking and now expressed a desire to pursue this as a career. He was accepted into a respected college and, the following September, began a new adventure. Unfortunately, Matt was unable to maintain the requirements of the program, missed one class too many and, three weeks before the end of his freshman year, was asked to leave. He then relocated to New Hampshire where he spent the summer working in a coastal tourist town. Matt decided to spend the winter in New Hampshire but seemed to spend most of his time unemployed and living out of his car. He spent one very cold week-end in lock-up for being with a companion who had been passing bad checks. The following August, Matt concluded that homelessness and poverty left a lot to be desired, so he headed south for New Jersey where his parents now lived.

During the next few years, Matt held many jobs, primarily in the food and catering industry. With help and support from his parents and aunt, he settled into his own apartment with a pet ferret. He made some new friends and re-acquainted himself with old ones, re-established relationships with his parents and aunt and, for the most part, grew up and achieved a great degree of independence. After several years of working in the food industry, Matt changed career paths and began working in customer services where new talents were discovered and cultivated. After his girlfriend moved to Boston, Matt decided it was time for him to return to his New England roots and moved there as well.

Matt's childhood and adolescence were stormy and unsettling. When he was about fifteen, Matt wanted to know what was "wrong" with him and why did he seem so different than his friends. His mom and aunt explained that his birth mom had drunk alcohol while she was pregnant and what the consequences had been for him. When Matt experiences an emotional low, he thinks about what greater heights he might have achieved and wonders, if he does have children, will they be like him?

Now, at age thirty, Matt has achieved a level of maturity that his parents and aunt had doubted he would ever be able to attain. From the three year old whose parents were told he would never learn, Matt has developed into a bright, articulate young man. His reading and comprehension abilities show evidence of great improvement, reinforcing recent proposals that our neurological systems continue to develop during young adulthood. Matt has learned to adapt and cope. He compensates for his tendency to be disorganized by making lists and checking them often. Matt's become the go-to guy when it's time to plan a trip or a camping week-end. He has hopes and aspirations. This young man has been in a steady and healthy relationship for over a year, has thoughts of getting married, having children and being a good father to them. He wants to be successful in a career and has recently returned to school to train to become an electrician. When Matt makes his mind up to do something, he can achieve his goal.

Matt has become much more than we ~ or his first neurologist ~ ever expected. While he certainly had a difficult adolescence, it is hard now to distinguish between what was extreme teen-age angst and what were severe consequences of prenatal exposure to alcohol. What is clear is that Streissguth's mitigating factors ~ a stable, loving home, early diagnosis, and access to appropriate services ~ were all present for Matt and greatly influenced his life. Today, Matt is in a "seriously committed" relationship, he is in the process of buying a house and he is completing the educational process to become a certified electrician. For a child and now adult who loves good food, we wonder what part nutrition may also have played in maximizing Matt's neurological development and thus his attainment of such a high degree of maturity and independence.

*Debbie Cohen*

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