

# Improving Awareness And Treatment Of Children With Fetal Alcohol Spectrum Disorders And Co-Occurring Psychiatric Disorders



*Prepared by*  
The Disability Service Center JBS International, Inc.



This project was supported by the Centers for Medicare and Medicaid Services (CMS) Community Alternatives to Psychiatric Residential Treatment Facilities Grant Demonstration Grants:

Alaska #ISOCMS300133

Georgia #ISOCMS300539

Indiana #ISOCMS300134

Kansas #ISOCMS300136

Maryland #ISOCMS300128

Mississippi #ISOCMS300129

Montana #ISOCMS300135

South Carolina #ISOCMS300131

Virginia #ISOCMS300137

The contents of this paper are solely the responsibility of the author and do not necessarily represent the official views of CMS.

### **Prepared by**

Eileen Elias, M.Ed., Director, Disability Service Center

### **Contributors**

Numerous people contributed to the development of this paper, including Anna Elizabeth Schmidt, Katie Weider, Donna Siu, Ruman Mustafa, Purva Jain, and Christine Muscolo who provided research support and Elliott Vanskike, Ph.D., and Katy McBride who provided editorial support.

### **Acknowledgments**

Special acknowledgments to Ronald Hendler, M.P.A., Technical Director of the Division of Community Systems Transformation at CMS, U.S. Department of Health and Human Services, and to Larke Huang, Ph.D., Senior Advisor in the Administrator's Office of Policy Planning and Innovation and Director of the Office of Behavioral Health Equity at the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

Appreciation to Barbara Knapp, Alaska PRTF Project Director and Sharon Cross, FASD Clinician for providing valuable input on child and adolescent with FASD treatment interventions.

The author would like to thank the staff at the Georgetown University National Technical Assistance Center for Children's Mental Health (TA Center) including Sherry Peters, M.S.W., A.C.S.W., Director of the PRTF Waiver Initiative; Jim Wotring, M.S.W., A.C.S.W., Director; and Diane Jacobstein, Ph.D., Senior Policy Associate.

June 2013

# **Improving Awareness and Treatment of Children With Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders**

Prepared by  
The Disability Service Center, JBS International, Inc.





## TABLE OF CONTENTS

Executive Summary .....	i
Introduction .....	1
A. Research, Diagnostic, and Treatment Challenges.....	2
B. Overview of Fetal Alcohol Spectrum Disorders.....	3
Diagnosis and Description of FASD .....	4
Trauma and FASD .....	6
Identification of Secondary Disabilities and Risk and Protective Factors .....	7
Inclusion of FASD in the <i>Diagnostic and Statistical Manual of Mental Disorders</i> .....	8
C. Experience of Children with FASD and Co-Occurring Psychiatric Disorders and Their Families .....	9
Challenges and Early Identification.....	9
Educational Challenges .....	10
Importance of an Accurate Diagnosis of FASD and Co-Occurring Psychiatric Disorders.....	12
Utilization of Inpatient Psychiatric Facilities by Children With FASD.....	13
Alaska’s Experience Using Its PRTF Demonstration Waiver to Treat Children With FASD .....	14
D. Research on FASD and Co-Occurring Psychiatric Disorders in Children.....	15
E. Reducing Alcohol-Exposed Pregnancies, Improving Clinical Awareness of FASD, and Enhancing Treatment Options for Children With FASD and Co-Occurring Disorders.....	18
Preventing Alcohol-Related Pregnancies .....	18
Improving Clinical Awareness .....	19
Enhancing Treatment Options for Children With FASD and Co-Occurring Psychiatric Disorders ....	21
F. Recommendations to Improve Identification and Treatment of Children With FASD and Co-Occurring Psychiatric Disorders.....	25
Research.....	26
Clinical Awareness.....	27
Prevention Programs.....	27
Treatment Interventions .....	28
Training.....	28
Leadership .....	28
References .....	30



## EXECUTIVE SUMMARY

The purposes of this paper are to increase understanding of the connection between serious emotional disturbances and fetal alcohol spectrum disorders (FASD) and to raise awareness of the unique diagnostic challenges and treatment needs of children who have FASD and co-occurring psychiatric disorders. (The term *co-occurring disorder* describes the presence of a psychiatric disorder and a disorder such as FASD that is related to substance use.) Robust studies of evidence-based interventions for this population are lacking. The main goal of this paper is to highlight both the lack of such studies and the pressing need for specialized interventions that can help address the challenges faced by children with psychiatric disorders within the FASD population.

FASD emerged as a description of a continuum of disorders associated with fetal alcohol syndrome (FAS) in the last 20 years; FAS itself was identified only in the 1970s. FAS was originally thought to be associated with distinctive facial features and cognitive deficits. But it is now understood that FAS can be present in those with normal intelligence and no physical markers, which complicates the diagnosis. FASD comprises various disorders that require a multidisciplinary team to properly diagnose. FASD has not been included in the forthcoming fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) as a full diagnostic category but is listed as a disorder that requires further study; this is a step on the way to full inclusion.

A challenging aspect of FASD is the psychiatric disorders that often accompany it. Mood disorders, major depression, psychosis, and personality or conduct disorders can co-occur with FASD. The fact that FASD can co-occur with psychiatric disorders is often why FASD is underdiagnosed in children receiving treatment, such as in Psychiatric Residential Treatment Facilities (PRTFs). In 2005, Congress funded State-based demonstration projects to determine whether children with serious emotional disorders who would normally be served in a PRTF could be treated successfully in a community-based setting. Nine states were funded to provide community alternatives to inpatient treatment in PRTFs. Mindful of the cognitive deficits experienced by children with FASD, the Alaska demonstration focused on modeling new behaviors that help ameliorate symptoms of serious emotional/psychiatric disorders for these children and ease transitions into employment and independent living.

Against the difficulty of diagnosing FASD and the under-recognition of psychiatric disorders in children with FASD is the very real knowledge that early diagnosis of FASD is one of the main protective factors, leading to twofold to fourfold decreases in adverse life outcomes (e.g., trouble with the law, confinement in jail or for treatment, repeated inappropriate sexual behavior, substance abuse) (Streissguth et al., 2004).

Early diagnosis must be followed by interventions that target the emotional/mental, behavioral, and educational needs of children with FASD and co-occurring psychiatric disorders. Bertrand

(2009) has compiled five behavioral interventions that show promise, and the American Psychiatric Association (APA), in its draft language for the DSM-5 (APA, 2012), surveys behavioral therapies and pharmacotherapies. The provisional inclusion of FASD in the DSM-5 (in its Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure section) may drive more research and heighten the profile of FASD.

Children with FASD are often thought to be defiant, aggressive, or out of control; in fact, they likely have central nervous system damage typical of FASD. Cognitive deficits and impaired executive function may make them poor learners.

The problems of children with FASD and co-occurring psychiatric disorders need to be addressed. In addition, researchers must study the programs that help prevent alcohol use during pregnancy and encourage the commitment of medical professionals, researchers, policymakers, and health administrators to reduce the effects of FASD on the lives of children and their families, as well as the social and financial cost to the Nation.

This paper addresses the following topic areas:

- Understanding the history and experience of children with FASD and psychiatric disorders, including those treated in PRTFs and other psychiatric institutions;
- Understanding the current state of research into psychiatric conditions that co-occur with FASD in children and proposed interventions;
- Understanding the importance of accurately diagnosing children with FASD and co-occurring psychiatric disorders so that they can be treated appropriately; and
- Recommendations to help children with FASD and co-occurring psychiatric disorders achieve their optimal functional status organized into the following categories: Research, Clinical Awareness, Prevention Programs, Treatment Interventions, Training, and Leadership.



**Improving Awareness and Treatment of Children  
With Fetal Alcohol Spectrum Disorders and  
Co-Occurring Psychiatric Disorders**



## **INTRODUCTION**

The fact that a mother's alcohol consumption during pregnancy can have harmful effects on the developing fetus has been a mainstay of medical literature in the U.S. for 40 years. Fetal alcohol syndrome (FAS) was widespread enough that the U.S. Congress tasked the Institute of Medicine (IOM) with investigating the problem. It is estimated that 1 baby in 100 in the U.S. is born with a neurodevelopmental disorder as a result of prenatal exposure to alcohol (May & Gossage, 2001). The disorders now grouped together as fetal alcohol spectrum disorders (FASD) are frequently cited as the most common preventable birth defects. The presence of FASD predisposes children to a variety of co-occurring psychiatric disorders (i.e., a psychiatric disorder that co-occurs with a disorder such as FASD that is related to substance use). While the breadth of the problem is apparent, there is a dearth of research that addresses it. The literature review for this paper identified only one large-scale study of children who had prenatal alcohol exposure (PAE) and co-occurring psychiatric disorders (Disney et al., 2008). There is also a consequent lack of evidence-based treatments available for this population.

In responding to a demonstration waiver from the Centers for Medicare and Medicaid Services (CMS) that was designed to move children with serious emotional disturbances out of psychiatric inpatient facilities and into community settings for treatment, the State of Alaska focused on children with FASD and co-occurring psychiatric disorders. By pairing each child with a mentor and bringing all the providers and social service agencies involved in the child's care together for training and education, the Alaska demonstration project was able to maintain this population of children in family settings, even though they met criteria for inpatient hospitalization. The success of the Alaska demonstration has implications for all inpatient psychiatric facilities, because children with FASD are over-represented in these facilities yet also frequently undiagnosed and inappropriately treated (American Psychiatric Association [APA], 2012). Alaska's commitment to addressing the needs of children with FASD and co-occurring serious emotional disorders is one of the motivating factors for writing this paper.

By highlighting the Alaska demonstration, this paper makes the case that successful interventions can be made with children with FASD and co-occurring psychiatric disorders, while at the same time it documents the lack of evidence-based practices to treat this population, especially when psychiatrically hospitalized. Experiences from Alaska are highlighted in the

textboxes throughout this paper. The paper opens by focusing on the unique challenges that come with FASD and then offers an overview of the history and diagnosis of FASD, along with a consideration of its provisional inclusion in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; APA, 2012). The paper then moves to a discussion of the importance of early diagnosis of FASD and a fuller consideration of the Alaska demonstration project. After surveying the state of the research on FASD and co-occurring psychiatric disorders in children, the paper discusses the importance of prevention, improved clinical awareness, and enhanced treatment options, including a review of five interventions shown to help this population. The paper concludes with wide-ranging recommendations on research, practice, and policy improvements that will result in increased evidence-based approaches to treat children with FASD and co-occurring psychiatric disorders.

## **A. RESEARCH, DIAGNOSTIC, AND TREATMENT CHALLENGES**

A recurring theme in research on individuals with FASD is the scarcity of studies that have focused on diagnosing and treating psychiatric disorders, especially given that a high percentage of children prenatally exposed to alcohol have psychiatric problems (O'Connor et al., 2002).<sup>\*</sup> O'Connor and colleagues referred to the lack of any study examining maternal drinking and mood disorders in children as a “major oversight” (O'Connor & Paley, 2009). Frankel and colleagues (2006) observed that there was no research on use of any medication other than psychostimulants to address activity level and attention in children with FASD. O'Connor and Paley (2006) examined the multiple co-occurring serious emotional/psychiatric disorders that often affect children with FASD and called for “a concerted and united effort by both researchers and clinicians to translate evidence-based interventions into more accessible, community-based services for individuals with FASDs and their families.” The purposes of this paper are to broaden the clinical understanding of serious emotional disturbances in young people with FASD and to drive research into evidence-based interventions for this population.

Diagnosis of FASD is often challenging because the traditional means of diagnosis—identifying facial characteristics or cognitive deficits—are unreliable (Jones et al., 1973). Many individuals

---

<sup>\*</sup> Due to the sparseness of the research on FASD and psychiatric disorders in children, it has been necessary to include references in this paper that are older than would be ideal.

with the various disorders that fall within FASD lack physical characteristics of the disorder and have normal IQs. When these children with PAE reach adulthood, they are more likely to have alcohol use disorders, based on self-reports of drinking quantity and frequency (Baer et al., 2003), which frames FASD as a generational problem. But this already difficult diagnosis is further complicated by the psychiatric disorders that so often co-occur with FASD, including mood disorders and clinical depression. In some studies, nearly 9 out of 10 children with FASD exhibit a psychiatric illness (O'Connor et al., 2002). Substance use often accompanies the psychiatric illness seen in young people with FASD. A 2003 survey of 26 States, though not specific to FASD and co-occurring psychiatric disorders, indicated that more than 20 percent of children and adolescents ages 12–17 admitted to hospitals for treatment of mental and/or substance use problems had co-occurring psychiatric and substance use disorders (Substance Abuse and Mental Health Services Administration [SAMHSA], 2011).

Even when individuals with FASD are accurately diagnosed, administrators, policymakers, and professionals in the medical, behavioral health, and educational fields are often unaware of the available treatment options, particularly for children with co-occurring psychiatric disorders receiving inpatient psychiatric services at psychiatric residential treatment facilities and other psychiatric institutions (Streissguth et al., 2004). Better treatment options are emerging, based on research studies designed and adapted specifically for individuals with FASD (Paley & O'Connor, 2011). Often, these interventions for children with FASD (e.g., educational and training sessions and counseling for those with FASD and their families) can be implemented through widely available community resources (Bertrand, 2009). There is still a need for more research on evidence-based approaches that are designed specifically for children with co-occurring FASD and psychiatric disorders, not adapted from work with similar populations.

## **B. OVERVIEW OF FETAL ALCOHOL SPECTRUM DISORDERS**

FASD is a complex disorder with a complicated history. FAS emerged as a diagnosis of physical and mental birth defects, but FASD has come to be understood as a continuum of disorders that always affect cognition but may not always have physical signs. Because psychiatric disorders often accompany FASD in children, understanding the roles of trauma and risk and protective factors can be integral to preventing and intervening in FASD and the psychiatric disorders with which it co-occurs.

## Diagnosis and Description of FASD

PAE is commonly cited as the leading preventable cause of birth defects and developmental disabilities in the United States. Children exposed to alcohol during fetal development can suffer multiple effects, ranging from subtle to serious, with lifelong negative consequences (National Center on Birth Defects and Developmental Disabilities [NCBDDD], 2004). Alcohol is a recognized teratogen (i.e., a substance that can cause congenital birth defects). Research continues to uphold the conclusion that there is no acceptable amount, type, or time for safe prenatal alcohol consumption (de Sanctis et al., 2011).

When FAS was first described in U.S. medical literature 40 years ago, the focus was on diagnosis through identification of physical characteristics. However, not all children with FAS look or behave the same, and the facial features associated with FAS may not occur or may soften as a child ages and be less apparent or disappear by adulthood (Jones et al., 1973). Because of concern about the breadth of the problem, the U.S. Congress asked the IOM to examine FAS with an eye toward, among other things, clarifying the diagnostic criteria. IOM's resulting 1996 study, *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*, led to widespread adoption of the umbrella term *fetal alcohol spectrum disorder* (Hoyme et al., 2005). This term describes the many effects that can occur in a child whose mother consumed alcohol during pregnancy; however, it is not a diagnosis. It refers to the following descriptions of overlapping conditions (IOM, 1996):

- FAS—Describes congenital mental and physical abnormalities that result from PAE, accompanied by slow growth and distinctive facial features (see below for more detail);
- Fetal alcohol effect (FAE)—Describes mental and behavioral effects of FAS without any physical signs;
- Alcohol-related birth defect (ARBD)—Describes congenital abnormalities linked to PAE; and
- Alcohol-related neurodevelopmental disorder (ARND)—Focuses on the central nervous system (CNS) and behavioral abnormalities of FASD and may be gaining favor over FAE and ARBD.

FAS is the only one of the conditions above that has been defined by the *International Statistical Classification of Diseases and Related Health Problems* (ICD) and assigned ICD-9 and ICD-10 diagnostic codes (World Health Organization, 2010). The prevalence of FAS in the United States is estimated to be between 0.5 and 2 per 1,000 births, and the prevalence of FAS, ARND, and ARBD combined is at least 10 per 1,000 or 1 percent of all births (May & Gossage, 2001). FASD can be considered the most common preventable form of acquired mental disability (de Sanctis et al., 2011).

The four criteria discussed in Table 1 are now widely accepted, and a diagnosis of FAS requires the presence of the first three criteria.

<b>Table 1: FAS Diagnostic Criteria</b>	
<b>Facial Abnormalities (Dysmorphia)</b>	Exhibits all three facial abnormalities: smooth philtrum (vertical grooves between the nose and upper lip), thin vermillion border (upper lip), small palpebral fissures (distance between the inner and outer corners of the eye); these abnormalities are sometimes called midline feature abnormalities, resulting from alcohol's interference with fetal nerve cell development
<b>Growth Deficits</b>	Confirmed prenatal or postnatal height, weight, or both at or below the 10 <sup>th</sup> percentile, adjusted for age, sex, gestational age, and race or ethnicity
<b>CNS Abnormalities</b>	Structural abnormalities (observed through imaging or head circumference at or below the 10 <sup>th</sup> percentile, adjusted for age and sex); neurological problems outside normal limits; functional performance below that expected for an individual's age, schooling, or circumstances
<b>Maternal Alcohol Exposure</b>	May be confirmed or unknown

Source: NCBDDD, 2004.

The effects of FASD may include physical, mental, behavioral, and learning disabilities (SAMHSA, 2006a). The Seattle Prospective Longitudinal Study on Alcohol and Pregnancy was funded in 1974 to examine the effects of PAE and has followed 415 offspring exposed to a range of prenatal alcohol levels. The Seattle study is a seminal longitudinal study referenced by much of the FASD research, and it is referred to throughout this paper. This research has demonstrated that PAE is associated with a number of secondary or co-occurring disabilities, of which mental illness is the most common (Streissguth et al., 1996). Life history interviews with 415 individuals with FASD found that 94 percent experienced mental/emotional disorders. During childhood, 60 percent of children with FASD had attention-deficit/hyperactivity disorder

(ADHD). During adulthood, most individuals with FASD experienced clinical depression. The study also revealed 23 percent of these adults had attempted suicide, and 43 percent had threatened to commit suicide (Streissguth et al., 1996).

## **Trauma and FASD**

Trauma plays a prominent role in FASD, both as a predisposing factor for women who drink during pregnancy and as an aftereffect for children diagnosed with FASD. A profile of 80 women in Washington State who had given birth to at least one child with FAS revealed several risk factors:

- 96 percent of the women had at least one mental disorder, including depression, phobias, and post-traumatic stress disorder;
- 95 percent had a history of sexual or physical abuse; and
- 80 percent lived with partners who did not want them to stop using substances.

Half of the women in the study had FAS conditions themselves (Astley et al., 2000). The research also found that 50 percent of those with FASD had undergone inpatient treatment for mental health or substance use problems or spent time in prison and that 24 percent of adolescents, 46 percent of adults, and 35 percent overall had substance use problems (Streissguth et al., 2004).

Breaking the cycle of trauma, substance abuse, and FASD requires an understanding of how women come to harmful substance abuse. Experiences of trauma or abuse typically precede mental disorders and significantly increase a woman's risk of substance abuse and addiction, because individuals tend to "self-medicate with alcohol, illegal drugs and/or prescription drugs" (Carlson, 2006, p. 99) to ameliorate emotional distress (Ashley et al., 2003; National Women's Health Resource Center, 2006). Research on adults with FASD found it likely that individuals will have a history of abuse, which can cause long-term damage to mental health and further impair the person's already compromised ability to form healthy relationships (SAMHSA, 2010).

Intervening in the generational pattern of trauma and PAE is part of the challenge facing State behavioral and public health and Medicaid agencies and health care providers. An additional



challenge is addressing the trauma faced by children with FASD. Children born with PAE are at higher risk for a range of psychiatric problems, in particular anxiety disorders, and these difficulties may become more pronounced as the children age into adolescence (Walthall, O'Connor, & Paley, 2008).

### **Identification of Secondary Disabilities and Risk and Protective Factors**

An effective way to mitigate the trauma experienced by children prenatally exposed to alcohol, including those with co-occurring psychiatric disorders, is to understand the risk and protective factors associated with FASD. The Seattle Prospective Longitudinal Study documented adverse postnatal environments and the corresponding risk of adverse life outcomes. For adolescents and adults, the life-span prevalence of adverse life outcomes was (Streissguth et al., 1996):

- 94 percent for mental disorders;
- 61 percent for disrupted school experience;
- 60 percent for trouble with the law;
- 50 percent for confinement (in detention, jail, prison, or a psychiatric or alcohol/drug inpatient setting);
- 49 percent for inappropriate sexual behaviors on repeated occasions; and
- 35 percent for alcohol/drug problems.

These risks are not mutually exclusive. An individual can experience multiple risk factors that can have a cumulative effect.

The research also identified protective factors that improve the chances of an individual achieving developmental potential:

- Early diagnosis before age 6;
- Living in a stable home with nurturing parents and minimum changes in household;
- Protection from witnessing or being victimized by violence; and
- Receiving developmental disability and behavioral health services.

Early diagnosis was the universal protective factor for all adverse life outcomes (Streissguth, et al., 1996). These studies suggest that accurate and early diagnosis of children with FASD may be a first step in reducing the risk of adverse and co-occurring outcomes.

### **Inclusion of FASD in the *Diagnostic and Statistical Manual of Mental Disorders***

The likelihood of obtaining an early diagnosis is hampered by health system issues, including a lack of clinical awareness and the absence of FASD in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), published in 1994 by APA. The DSM contains a list of psychiatric disorders and their diagnostic criteria and descriptive text, along with diagnostic codes used for research, insurance claims, data collection, and medical records. Psychiatrists, psychologists, and other behavioral health professionals use this primary reference tool as a guideline for diagnosis (Minnesota Organization on Fetal Alcohol Syndrome, 2008). So central is the DSM to the diagnosis of disorders and the process of billing for payment that a disorder's absence from the DSM can contribute to its being overlooked and underdiagnosed.

Revising the DSM is typically a lengthy process. The fifth edition, DSM-5, scheduled for publication on May 18, 2013, will address the need for FASD mental health diagnostics by including Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure in Section III, an area devoted to conditions that require further research before consideration as formal disorders (APA, 2012). FASD is defined in DSM-5 by exposure to alcohol during gestation, neurocognitive impairment, impairment in self-regulation, and deficits in adaptive functioning that are apparent before age 18 and contribute to clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Although individuals presenting with these conditions will not be provided with a formal diagnosis through the DSM-5, conditions requiring further research are expected to generate increased clinical awareness. Binge eating disorder is an example of a condition included in DSM-IV as needing further study that will be formally recognized as a disorder in DSM-5. Ideally, FASD would follow a similar trajectory: inclusion in Section III of DSM-5, followed by full recognition of the disorder in the subsequent edition.

The APA's rationale for including FASD in conditions requiring further study acknowledges the concerns raised by State and national medical and advocacy organizations about the problems associated with FASD's exclusion from the DSM:

Although the IOM's diagnostic coding schema has been useful in delineating the variation in the physical characteristics associated with PAE, it does not adequately provide a method of describing the neurodevelopmental and mental health symptoms associated with PAE. As a result, the service needs of many children with PAE are not identified or are often inappropriately treated by mental health professionals. The term *Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)* is a new clarifying term, intended to encompass the full range of developmental disabilities associated with exposure to alcohol in utero. The current diagnostic guidelines allow ND-PAE to be diagnosed both in the presence or absence of the physical effects of PAE.

The omission from the DSM of a diagnosis describing this constellation of impairments has likely contributed to the difficulty many of these individuals and their families experience in accessing appropriate services for mental health issues. Of particular concern, individuals impacted by PAE are significantly over-represented yet under-recognized in the child welfare system, juvenile detention and correctional facilities, and inpatient psychiatric settings. Many of these individuals are seen in outpatient mental health settings, but are often not appropriately identified. Consequently, these individuals are frequently treated inappropriately (often to their considerable detriment) by mental health, educational, and criminal justice systems. (APA, 2012)

Including FASD in the DSM-5 provisionally, with a path toward full inclusion, is expected to raise clinical awareness; improve communication among clinicians, patients, and families; assist in the study of pathophysiology and etiology; guide treatment; and avoid the development of secondary disabilities by early identification and appropriate treatment over the life span (IOM, 1996). Although FASD's provisional inclusion in the DSM is encouraging, such inclusion speaks to the disorder's ongoing liminal status in the medical and psychiatric communities.

## **C. EXPERIENCE OF CHILDREN WITH FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS AND THEIR FAMILIES**

### **Challenges and Early Identification**

Early diagnosis improves outcomes for children with FASD, but it poses difficulties because FASD is a birth defect that primarily affects the brain. Deficits in CNS areas can lead to maladaptive behaviors and mental disorders that may trigger referral and diagnostic evaluation. The effects of FASD may not be recognized or may be mislabeled as stubbornness or "bad" behaviors by caregivers, teachers, and family members (SAMHSA, 2004) as identified in the

Alaska Psychiatric Residential Treatment Facilities (PRTF) waiver demonstration. Children with FASD may develop secondary symptoms that include being fatigued, frustrated, and angry; shutting down or blaming others; and poor self-esteem, isolation, and depression (Malbin, 2008).

Behavioral problems caused by brain damage from PAE are mistakenly assessed as resulting from difficulties in the home environment (National Organization on Fetal Alcohol Syndrome [NOFAS], 2006f). The potential for a congenital mental disorder resulting from FASD to be “acting out” is complicated in that the majority of children with FASD have unstable home environments. A study found that 80 percent of children with FASD were not with their birth parents (Streissguth et al., 1996). Children in homes where adults abuse substances are more likely to spend longer periods in foster care than other children (11 months versus 5 months).

## **Educational Challenges**

Most students with FASD have normal or above average IQs, including those with co-occurring disorders, although they often have problems receiving and processing information and attention and memory problems. Often they cannot store what they learn or lack the mental capacity to use information they have been given (Jacobson & Jacobson, 2002). For these reasons, many children with FASD are not diagnosed until elementary school, at which point the gap between physical and developmental ages becomes apparent. Many are referred because of suspected learning disabilities (NOFAS, 2006e). Early diagnosis has been shown to be a protective factor that can reduce later FASD adverse outcomes. Delaying a diagnosis until children reach school age may have detrimental effects on academic prospects and psychiatric and emotional well-being. Table 2 provides an overview of social and academic challenges students with FASD face.

<b>Table 2: Behaviors Typical of Those With FASD (From Infants Through Teenagers)</b>	
<b>Infants</b>	Low birth weight; irritability; sensitivity to light, noise, and touch; poor sucking; slow development; poor sleep-wake cycle; increased ear infections
<b>Toddlers</b>	Poor memory capability, hyperactivity, lack of fear, no sense of boundaries, need for excessive physical contact
<b>Young Children</b>	Short attention, poor coordination, difficulty with motor skills, unable to understand cause/effect and multiple directions/rules, difficulty with math/abstract reasoning
<b>Older Children</b>	Trouble keeping up with school, low self-esteem from recognizing they are different from their peers
<b>Teenagers</b>	Poor impulse control, cannot distinguish between public/private behaviors, need daily reminders

Source: NOFAS, 2006b; SAMHSA, 2004.

Because of auditory processing problems and impaired executive function, these students may not respond to traditional teaching methods such as lectures. They may act out in frustration

“The youth who experience FASD and co-occurring psychiatric and often have difficulty in every arena of their life. They have difficulty learning from their experiences. They have difficulty following through, paying attention, tending to what’s going on. The Alaska waiver program provided the opportunity to have an individual mentor to be with the youth to help them to learn to compensate in every area. The mentor was able to enrich their activities, to help them to stay on track, to help them to stay on task, to help them to learn from their mistakes, to help them to focus on what they’re doing.”  
— Drenda Tigner, Executive Director of an Alaska mental health and social services provider agency.

because they do not understand what is going on, “melt down” due to sensory overload, fidget, and struggle in, for example, math class. Most do not learn from negative reinforcement because they cannot generalize rules. Many have impulse control problems. Children with FASD typically lack social skills, such as listening, asking for help, waiting their turn, and sharing (SAMHSA, 2004), as identified by the Alaska PRTF waiver demonstration.

Students with FASD face an additional educational challenge because the diagnosis is not a recognized Federal category for special education. Individuals with PAE and IQs greater than 70 may not qualify for educational support services, despite evidence they perform poorly on

tests or have complex attention, verbal learning, and executive function deficits. Conversely, children with FASD who score poorly on intelligence tests suffer learning deficits that are not solely attributable to their lower IQs (Kerns et al., 1997). These children and their families and caregivers must contend with FASD as it affects learning and with the fact that learning difficulties resulting from FASD are typically not identified as needing special education attention or funding. Looking only at the impaired cognition caused by FASD, these findings argue for including evaluations of children with FASD as part of other learning disorders.

In addition to having impaired cognition, children with FASD and co-occurring psychiatric disorders are often mistakenly diagnosed as having ADHD, because the co-occurring disorder can cause learning and behavior problems similar to ADHD. According to the National Institute of Mental Health (NIMH), ADHD is one of the most common childhood mental disorders, persisting into adolescence or adulthood (NIMH, n.d.). Research to differentiate between FASD

and ADHD focuses on a behavior called *perseveration*—an impaired ability to shift from one task to another (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2011). An NIAAA review of research studies comparing children with FASD to children with ADHD found that (NIAAA, 2011):

- Children with ADHD have more difficulties focusing and sustaining attention from one task to another, whereas children with FASD find it harder to shift attention from one task to another and solve problems with flexibility.
- Children with ADHD have trouble retrieving information they learned verbally, whereas children with FASD have trouble encoding and remembering verbally learned information.

In a review of pharmacotherapy for FASD in preparation for including it in Section III of DSM-5, the APA found that medications used to treat ADHD produce mixed results when used for children with FASD. Specifically, it concluded that children with FASD appeared to have a differential response to methylphenidate and dexamphetamine. For example, psychostimulants, which often reduce inattention symptoms in children with ADHD, are not as effective for children with FASD (APA, 2012).

### **Importance of an Accurate Diagnosis of FASD and Co-Occurring Psychiatric Disorders**

According to the NIAAA, FASD is chronically underdiagnosed because “distinguishing FASD from other developmental disorders is tricky, and evolving diagnostic standards are not yet accepted by everyone” (NIAAA, 2011). Making this differential diagnosis is further complicated because psychiatric disorders often co-occur with FASD. Researchers are finding that children with PAE are at high risk for developing major psychiatric co-occurring disorders (O’Connor et al., 2006). These co-occurring disorders can complicate treatment and interfere with the person’s ability to function (SAMHSA, 2006b). Failure to recognize co-occurring disorders can increase the risks of inappropriate treatment and psychiatric hospitalizations, along with other adverse outcomes (SAMHSA, 2006b). Because the signs and symptoms of FASD are similar to those of some mental illnesses, it is important to determine whether the symptoms are a result of PAE or have another root cause. FASD can co-occur with many psychiatric disorders such as (O’Connor & Paley, 2009; SAMHSA, 2006b):

- Major depressive disorder or bipolar disorder;
- Mood disorders;
- Psychotic disorders (e.g., schizophrenia);
- Anxiety;
- Suicidal thoughts;
- Personality or conduct disorders; and
- Reactive attachment disorder.

Often an individual with FASD and a co-occurring psychiatric disorder is not diagnosed with FASD. For insurance purposes, providers may list a co-occurring mental illness as the primary diagnosis. Because of the complexity of the diagnosis, ideally, individuals with FASD should be diagnosed through a multidisciplinary team consisting of one or more medical doctors; psychologists, psychiatrists, and social workers; speech language specialists and occupational therapists; and education specialists. Because the life skills affected by PAE vary greatly, appropriate interventions need to be tailored to each child with FASD and his/her family (NOFAS, 2006c). Children with FASD and co-occurring psychiatric disorders have complicated special needs requiring significant skill in caring for them and complex case management (O'Connor et al., 2006).

### **Utilization of Inpatient Psychiatric Facilities by Children With FASD**

Even though PAE results in significant risk for co-occurring mental illnesses, under-recognition of these children in psychiatric settings is common. A PRTF is any non-hospital facility with a provider agreement with a State Medicaid Agency to provide the inpatient services benefit to Medicaid-eligible individuals under the age of 21 (CMS, n.d.). PRTFs represent one of the most restrictive inpatient settings for psychiatric treatment of children. Young people who find themselves in a PRTF often have engaged in dangerous behavior to themselves or others (e.g., fire setting or self-destruction) or run away from foster care. Although it is true that children are placed in a PRTF because they have highly complex needs, children with FASD and co-occurring psychiatric disorders often go undiagnosed. One of the first and most significant studies of children with psychiatric disorders and possible FASD was a chart review of 130 admissions to a large university medical school's child psychiatry inpatient service; this study showed that children with FAS may be overrepresented in inpatient psychiatric settings

(O'Connor et al., 2006). The study sought to determine the number of children with a history of PAE among a general sample of child psychiatric inpatients and compare children who were exposed to alcohol with children without exposure on psychiatric diagnosis and other characteristics. The study found that 30 percent of these inpatients had documented PAE. Furthermore, one in four of the children exposed to alcohol met criteria for FAS, although none had been diagnosed with FAS before admission. Multiple encounters with inpatient psychiatric facilities by children with FASD led not only to an external stigma because of psychiatric disorders, but also to diminished self-perceptions, histories of multiple treatment failures, and higher costs that could be reduced with appropriate diagnoses.

### **Alaska's Experience Using Its PRTF Demonstration Waiver to Treat Children With FASD**

In 2005, Congress authorized a 5-year demonstration grant project to test whether children with serious emotional disturbance who meet the requirements to be served in a PRTF could be served with their families or in family settings in the community in a successful and cost-effective manner, using a 1915(c) Home and Community-based demonstration waiver. The CMS selected nine States to participate in this demonstration (Alaska, Georgia,

"The goal of the Alaska waiver demonstration was to address the unique treatment needs of children and youth with FASD, who often have longer lengths of stay and less functional status in PRTFs in comparison to youth who do not have a FASD diagnosis. Historically, Alaska has placed children with FASD with more severe co-occurring behavioral disorders in out-of-State PRTFs, oftentimes in States such as Texas, Utah, Colorado, Montana, Oregon, and Florida. However, many out-of-State PRTF/ residential care facilities do not address FASD so these individuals were less likely to receive appropriate interventions.... [B]y properly diagnosing and identifying children with FASD who meet the level of care criteria for Alaska's PRTFs, the waiver demonstration has been able to retain these children in-State and provide more appropriate treatment interventions and community-based continuity of care."

Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia). The nine States provided community alternatives to residential treatment to more than 5,000 children by July 2012, the fifth and final year of the demonstration. One of the states, Alaska, proposed to serve children who had an additional challenge beyond the serious emotional disturbance—the challenge of existing or suspected FASD. The other eight States in the demonstration, focused on prevention efforts with education and public health campaigns to reduce alcohol use during



pregnancy. Alaska decided to go beyond prevention and implement a program that addressed the treatment needs and challenges of children with FASD. Even before the demonstration, leaders and providers in State behavioral health care and Medicaid, as well as family member advocates and family stakeholders, in Alaska had been focusing on ways to increase awareness of the special challenges presented by children with FASD and find ways to improve outcomes for these children. For example, there are multiple FASD Diagnostic Centers across Alaska, some focusing on Native Alaskans and others treating non-native children as well. These centers are attuned to cultural issues, and many have bilingual professionals. A high percentage of the children in Alaska's demonstration were in foster homes and adoptive homes due to safety concerns with ongoing alcohol abuse.

#### **D. RESEARCH ON FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS IN CHILDREN**

There is abundant literature on neurocognitive deficits of individuals with PAE that focuses on response inhibition, attention, memory, and executive functioning. But there has been comparatively little research on co-occurring FASD and the psychiatric functioning of this population. Studies have reported precursors to psychiatric disorders, including internalizing (depression, anxiety) and externalizing (hyperactivity, poor impulse control) behaviors, as well as insecure attachments (O'Connor et al., 2006). Studies of psychiatric functioning in children with PAE are relatively sparse, and those that have been conducted have had relatively small sample sizes:

- A study found that, of 23 middle school children referred to the University of California at Los Angeles (UCLA) FASD Clinic, 87 percent met criteria for a psychiatric disorder. Sixty-one percent of those meeting the criteria for a psychiatric disorder were assigned a mood disorder diagnosis; 27 percent were diagnosed with major depressive disorder or adjustment disorder with depressed mood; and 35 percent met criteria for bipolar disorder (O'Connor et al., 2002).
- A UCLA study of 42 children ages 4 and 5 and their biological mothers found that children whose mothers reported moderate to heavy alcohol consumption during pregnancy reported significantly higher levels of depressive symptoms than children

whose mothers reported abstinence or light alcohol consumption during pregnancy (O'Connor & Paley, 2006).

- A study at the University of California at San Diego compared 39 children with heavy PAE with 30 non-exposed control children and found that 97 percent of the children exposed to alcohol met the criteria for at least one mental disorder compared with 40 percent of the control children. The majority (59 percent) of the children exposed to alcohol had externalizing disorders such as ADHD, oppositional defiant disorder, or conduct disorder, whereas 21 percent met the criteria for an anxiety disorder and 7 percent for a mood disorder. More important, although 97 percent of the children exposed to alcohol had a mental disorder, only 40 percent of these children had been evaluated for or previously received a psychiatric diagnosis (Fryer et al., 2007).
- A UCLA study of 130 children between ages 6 and 12 found that children with PAE exhibited significantly more psychopathology symptoms, including anxiety, disruptive behaviors, and mood disorders, when compared with children without PAE (Walthall et al., 2008).
- Individuals diagnosed with FASD have neuropsychological deficits that may contribute to psychosocial and mental health problems at every developmental stage, including increased risk for suicide. To help clinicians recognize the patterns that signal potential for suicide, researchers using the Seattle Prospective Longitudinal Study prepared clinical profiles of 11 individuals to differentiate the 6 who made suicide attempts from the 5 who did not. Individuals who attempted suicide were more likely to have mental disorders, substance use disorders, a history of trauma or abuse, financial stress, and unstable social support compared with those who did not attempt suicide. The study also discusses ways in which clinicians can reduce risk among individuals with FASD by modifying standard suicide assessment and intervention protocols to accommodate the person's deficits (Huggins et al., 2008).

The only large-scale study to date used data from the Minnesota Twin Family Study (an ongoing population-based, longitudinal investigation that began in 1987) to examine 1,252 adolescents and their parents who had completed diagnostic interviews to generate lifetime psychiatric

diagnoses. PAE was associated with higher levels of conduct disorder symptoms (e.g., defiant or impulsive behavior, lying, inability to follow rules), even after controlling for environmental factors associated with parents who drink, such as illicit substance use, alcohol dependence, and antisocial behavior (Disney et al., 2008).

All of these studies establish a credible link between PAE and impaired psychiatric functioning and underscore the need for psychological evaluation of individuals with histories of PAE to prevent misdiagnosed or undetected co-occurring mental disorders. The studies also argue persuasively and explicitly for more effective programs targeted to reduce the amount of alcohol women consume during pregnancy. They are, however, largely silent on effective interventions that can be used to treat children who have mental disorders as a result of PAE. These studies highlight the need for increased research with larger participant numbers to validate evidence-based practices in treating children, youth, and young adults with FASD and co-occurring substance use and psychiatric disorders, including those in in-patient psychiatric settings, as supported by new promising practices resulting from the Alaska PRTF waiver demonstration.

The successes of the Alaska waiver were twofold:

- Children served in the FASD waiver who were diverted or transitioned from PRTFs were able to be maintained in the community, even though they met the level of care to be admitted to or remain in a PRTF. This was especially notable because prior to the waiver the children who were served in PRTFs often had longer lengths of stay in the residential setting or the children were returned to the residential setting soon after discharge to the community. Many of these children were also diverted from the juvenile system due to their successful treatment in the community.
- Due to increased training and educational efforts with provider agencies that were involved in multiple child-serving systems, children not connected to the waiver benefited from the increased awareness of how FASD affects behavior and how their attitude changes along with modified interventions could help the children to be successful.

## **E. REDUCING ALCOHOL-EXPOSED PREGNANCIES, IMPROVING CLINICAL AWARENESS OF FASD, AND ENHANCING TREATMENT OPTIONS FOR CHILDREN WITH FASD AND CO-OCCURRING DISORDERS**

### **Preventing Alcohol-Related Pregnancies**

For 40 years Federal, State, and community organizations have tried to prevent alcohol-exposed pregnancies and reduce the most preventable cause of birth defects and developmental disabilities in the United States (Gahagan et al., 2006). The first advisory warning on alcohol use in pregnancy was issued by the Surgeon General in 1981, and it was strengthened most recently in 2005 (U.S. Department of Health and Human Services, 2005). States initiated alcohol beverage warning labels in 1989, and many States have extended this strategy by enacting laws requiring posted warnings at point of sale for alcoholic beverages. As antismoking initiatives have demonstrated, changing social and cultural norms is one of the most effective ways to reduce deleterious behaviors but remains a challenge for the following reasons (FASD Regional Training Centers Consortium, 2007):

- Nearly half of all pregnancies are unplanned.
- More than half of all women of childbearing age who are sexually active and not using effective measures to prevent pregnancy reported alcohol use; 12 percent reported binge drinking.
- Among pregnant women, 10 percent reported alcohol use and almost 2 percent reported binge drinking.

Prevention strategies targeting high-risk subgroups, such as women of childbearing age who misuse alcohol, have been conducted in a variety of settings including primary care, emergency departments, and colleges (Centers for Disease Control and Prevention [CDC], 2009). Screening in clinical settings, coupled with brief interventions or referral for treatment of alcohol abuse have been found to be an effective prevention strategy for helping to prevent FASD. Key elements of such brief interventions include use of feedback on drinking behavior, advice to change, goal setting, follow-up contacts, and provider training (CDC, 2009). Project CHOICES (Changing High-Risk AlcOhol Use and Increasing Contraception Effectiveness Study), sponsored by the CDC in the 1990s, was one of the first studies to target a group at risk for both contraceptive and alcohol use patterns, using motivational interventions that consisted of four counseling sessions designed to reduce women's alcohol intake and a session on contraceptive

methods. Promising results from this study have led to additional dual-use studies (CDC, n.d.). Bright Futures is another such program, focused broadly on health promotion and prevention among children in the context of family and community. Bright Futures was launched in 1990 by the Maternal and Child Health Bureau of the Health Resources and Services Administration. Involved since Bright Futures' inception, the American Academy of Pediatrics (AAP) began to coordinate the program's efforts in clinically based prevention at the local, State, and national levels. Guidelines and tools supported by Bright Futures strengthen the connections among health promotion programs at all levels, and among pediatric primary care, families, and local communities (<http://brightfutures.aap.org/>).

Women at highest risk for having a child with FASD are mothers who have previously given birth to a child affected by alcohol (Astley et al., 2000). Reaching these high-risk women is often difficult, and their treatment is complex. Onsite therapeutic treatment for alcohol and drugs, prenatal care, case management, childcare, transportation, and comprehensive support services are factors that enhance positive outcomes for child and mother (Astley et al., 2000).

### **Improving Clinical Awareness**

Barriers to identification of alcohol consumption during pregnancy in the clinical setting come from both patients and health care providers. Some women who drink during pregnancy are deterred from seeking prenatal care and substance use treatment due to shame, fear of prosecution, and loss of their children to child protective services (NOFAS, 2006a). Health care professionals have a crucial role in identifying women at risk for an alcohol-exposed pregnancy and in identifying effects of PAE among individuals. But screening for alcohol use among female patients of childbearing age and diagnosis of FAS and related conditions are not common practices of care (FASD Regional Training Centers Consortium, 2007). Although many physicians report that they assess for PAE, many do not use standardized screening tools, and a significant number do not routinely inquire about alcohol use at all (Diekman et al., 2000). Data from the CDC's Behavioral Risk Factor Surveillance System show that, although 70 percent of smokers had been advised to quit by their health care provider, only 23 percent of binge drinkers had been warned about their alcohol use (NOFAS, 2006a). A CDC survey with the AAP found that 62 percent of respondents felt prepared to identify, 50 percent felt prepared to diagnose, and only 34 percent felt prepared to manage and coordinate the treatment of children with FASD

(Gahagan et al., 2006). To address the lack of clinical awareness and communication, the CDC funded a consortium of five universities as FASD Regional Training Centers, including the University of Alaska–Anchorage; the University of Nevada–Reno; the University of Wisconsin School of Medicine and Public Health; the Midwestern FASD Regional Training Center (comprising St. Louis University, University of Arkansas Medical Sciences, University of Oklahoma Health Sciences Center, and Nurses for Newborns Foundation); and the Southeastern FASD Regional Training Center (comprising Meharry Medical College, Morehouse School of Medicine, University of Tennessee, University of Louisville, and Tennessee State University). These centers were created to develop, implement, and evaluate educational curricula for medical and allied health students and practitioners (FASD Regional Training Centers Consortium, 2007). This program continues with the five regional centers funded through 2014: Arctic FASD Regional Training Center at the University of Alaska–Anchorage; Frontier FASD Regional Training Center at the University of Nevada–Reno; Great Lakes FASD Regional Training Center at the University of Wisconsin; Midwestern FASD Regional Training Center at St. Louis University; and Southeastern FASD Regional Training Center at Meharry Medical College (Nashville, Tennessee).

A 2009 study of 308 psychiatric trainees from across the United States raises even more worrisome findings for the identification and treatment of individuals with FASD and psychiatric disorders:

On the basis of the survey results, it is clear that profound under-recognition of FASDs in psychiatric training programs is a national problem. Although respondents reported seeing hundreds of patients in clinical settings, and the majority had knowledge of the defining characteristics of FAS, an overwhelming majority reported never having diagnosed an FASD.

Studies have shown clear overrepresentation of people affected by FASD in psychiatric settings, so trainees are treating these individuals without a fundamental understanding of the nature of their illness.

This under-recognition represents missed opportunities for intervention and prevention. Such failures to lessen the impact of this devastating disease in high-risk groups such as psychiatric patients are tragic. (Eyal & O'Connor, 2011)

Trainees who indicated they had received supervision specifically addressing FASD reported making the diagnosis much more frequently. This suggests that supervision in a clinical setting is an effective means of increasing diagnostic skills and knowledge (Eyal & O'Connor, 2011).

## **Enhancing Treatment Options for Children With FASD and Co-Occurring Psychiatric Disorders**

Families of those affected by FASD often report that clinicians are reluctant to diagnose children because there are no known effective treatments. The lack of effective interventions is

“The value of the Alaska waiver demonstration goes beyond the number of participants in the program... by increasing awareness and better diagnosis and treatment of all children with FASD, not just those that meet the level of care criteria for PRTF placements.”—Barbara Knapp, Project Director

attributable, in part, to the fact that initial strategies were taken from work with children with other disabilities and from the trial-and-error experience transferred through informal networks of parents and clinicians. Difficulties with diagnosis and the lack of research into effective interventions have been a source of ongoing frustration for parents and family members of children with FASD (Bertrand, 2009). Because multiple generations within the same family could be affected by PAE, interventions are needed that also

focus on providing resources, education, training, and even direct services to caregivers to maximize their functioning (Paley & O'Connor, 2009).

In recent years, there has been an increase in efforts to design and test interventions for individuals with FASD to address social and behavioral challenges and to begin addressing psychiatric functioning (Paley & O'Connor, 2011). PAE can result in structural brain damage that leads to CNS dysfunction. There is a high prevalence of co-occurring psychiatric disorders among children with FASD, including depressive and bipolar disorders, mood and anxiety disorders, and psychotic disorders, such as schizophrenia (O'Connor & Paley, 2009). The co-occurrence of psychiatric disorders with FASD argues for the urgency of adapting the practices described below for this population and developing new evidence-based practices.

**Innovative Interventions for Children With FASD**

The following five interventions were the first that were scientifically designed and adapted for children with FASD. They demonstrate a variety of interventions to improve the lives of children with FASD, reduce conditions secondary to FASD, and enhance the lives of families affected by FASD (Bertrand, 2009). Although these interventions are specific to children with FASD, they have been found to also help treat children with FASD and co-occurring psychiatric and substance abuse disorders.

***Social Skills Training Program To Improve Peer Friendships for Children With FASD***

One of the first systematic evaluations of treatment for improving social functioning was a study conducted at UCLA on the effects of parent-assisted friendship training. Many children with FASD have considerable social impairment, such as problems understanding social cues, indiscriminate social behavior, and difficulty communicating in social contexts, even after controlling for differences in cognitive functioning. In this study parents facilitated their children's social skills in network formation, peer exchanges, entry into play groups, in-home play dates, and conflict avoidance and negotiation. Following treatment, parents reported more knowledge about their children's condition and a high level of satisfaction with the intervention. Children showed significant improvement in their knowledge of appropriate social skills and decreasing problem behaviors (Bertrand, 2009).

***Training To Improve Behavioral and Mathematical Functioning in Children With FASD***

Deficits in mathematical training have been consistently reported for children affected by alcohol. A Georgia study developed a program to facilitate mathematics learning through intensive, short-term individual instruction, together with caregiver and teacher training. A goal of the study was to provide consistent teaching of mathematical concepts across therapeutic, home, and school environments. Results indicated the parent-training component was well received and associated with reports of improved behaviors by the children in the study. It also suggested that effective teaching methods could improve learning for children with deficits related to alcohol exposure (Bertrand, 2009).



*Neurocognitive Habilitation for Children With FASD Who Are in Foster Care or Have Been Adopted*

Children in foster care are more likely than the general population to have FASD, and foster care is part of the developmental history of many children who are eventually adopted. This study at Children's Research Triangle provided education and support to enhance the families' capabilities to care for the children and focused on improving the children's executive functioning through improved self-regulation. The curriculum combined self-regulation techniques and tools to improve memory, cause-and-effect reasoning, sequencing, planning, and problem solving. Children who participated in the program demonstrated significant improvement in executive functioning compared with a control group of children (Bertrand, 2009).

*Parent–Child Interaction Therapy Adapted To Reduce Behavior Problems in Children With FASD*

The difficult behaviors seen among children with FASD, together with the caregiver's negative perceptions and stress, often have a detrimental impact on the child's development. This study at the University of Oklahoma Health Sciences Center evaluated two group-based interventions to decrease parental stress and reduce behavior problems among children with FASD, particularly young children. One group provided parents and children with a live, coached practice of behavioral parenting skills (this was a group adaptation of an evidenced-based behavioral parent training treatment, Parent–Child Interaction Therapy). The other group was a parent-only Parenting Support and Management program. Improvements in parental stress and in child behavior problems were noted with both interventions, with no statistically significant differences between interventions. Bertrand proposes that the parenting support format might prove more cost effective and easier to implement, which would make it suitable for community settings (Bertrand, 2009).

*Behavioral Consultation To Improve Outcomes for Families Raising Children With FASD*

Interventions are especially important for caregivers raising preschool- and school-age children with FASD who have challenging behaviors and signs of family and school disruption. Parents struggle to achieve positive parenting attitudes, find and use effective parenting skills, acquire specialized knowledge, and make effective linkages to appropriate school and community resources. In this study, parents were taught to “brainstorm” parent-friendly supports to deal with challenging behaviors and to advocate for “accommodations” in the child's physical and

caregiving environment. The program helped parents reframe their understanding of the child's behaviors as neurodevelopmental disabilities rather than willful disobedience. Caregivers enrolled in the study showed a significantly improved sense of parenting effectiveness. Children in the intervention group showed a significantly decreased number of challenging behaviors (Bertrand, 2009).

At least three overarching themes have emerged from these studies. First, children with FASD have impaired CNS functioning resulting in a complexity and severity of challenges that make it essential to develop a broad range of evidence-based interventions. It bears repeating that children with co-occurring disorders would see substantial benefit from these evidence-based interventions as well. Second, there is tremendous value in including parents and caregivers as active participants and collaborators. In fact, parent education or training was a component that was deemed essential to the success of all five interventions. Children with FASD may not respond to the usual parenting practices. Parents benefit from education about their children's disabilities and ways to reach and teach their children. Finally, interventions can be implemented within a framework of typically available community services, such as schools, social services, or mental health facilities (Bertrand, 2009).

### **Pharmacological Interventions and Case Management**

Two other areas should be included in any discussion of psychiatric treatment and intervention for children with co-occurring FASD and mental/emotional disorders: pharmacological interventions and case management.

#### ***Pharmacological Interventions***

Because children with FASD are at elevated risk for disruptive behavior problems, mood disorders, substance use and abuse, and psychiatric hospitalization, it is not surprising that such children often receive pharmacological interventions. The empirical support for the efficacy of these medications in FASD is limited (Paley & O'Connor, 2009). In an unpublished study examining the medication status of 163 consecutive inpatient admissions to the UCLA Child Psychiatric Inpatient Service, children with PAE averaged 2.56 medications on admission compared with unexposed children who averaged 1.68 medications on admission (O'Connor, unpublished raw data; Paley & O'Connor, 2009). Additional research on the efficacy of stimulants and other classes of medications is needed, including studies to decrease the

likelihood of medication mismanagement and adverse reactions for these individuals with FASD (Paley & O'Connor, 2009). Further research into pharmacological interventions for children with FASD and co-occurring psychiatric disorders is also called for.

Frankel and colleagues (2006) found that the efficacy of social skills training was enhanced in a population of 6- to 14-year-olds with FASD when the children were given neuroleptics. Because PAE is linked to disturbance of the neurotransmitters dopamine and noradrenaline, the researchers theorized that drugs that suppressed the activity of dopamine and serotonin would support improvements in measures of self-control and problem behaviors, as reported by parents and teachers. When neuroleptics (primarily risperidone, which is mainly used to treat schizophrenia and bipolar disorder) were prescribed, enhancements were seen in responses to children's friendship training, a social skills intervention that consisted of how to have a two-way conversation, how to join other children at play, how to be a good sport, how to be a good host on a play date, and how to handle being teased.

### **Case Management**

Case management for children who are exposed to alcohol focuses on the extensive psychiatric issues often seen in this population. As cited earlier, in a longitudinal study tracking adverse outcomes of adolescents and adults with FAS or FAE, 94 percent of the individuals were found to have experienced mental health problems (Streissguth et al., 1996). Researchers have also noted that many of the risk factors commonly cited for suicide are present in individuals exposed to alcohol (Huggins et al., 2008). The 1996 study of individuals with FAS or FAE also found that 66 percent had threatened or attempted suicide (Streissguth et al., 1996). The serious psychiatric issues commonly seen in those with FASD underscore the need for comprehensive case management that incorporates psychosocial interventions and services aimed at preventing relapse (Paley & O'Connor, 2009).

## **F. RECOMMENDATIONS TO IMPROVE IDENTIFICATION AND TREATMENT OF CHILDREN WITH FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS**

The immense personal, social, and health economic burdens created by FASD underscore the urgent need for administrators, policymakers, and professionals in the medical, mental health, and educational fields to respond to the needs of children with co-occurring psychiatric disorders

across multiple domains. The problem is wide ranging, so the recommendations that follow are of necessity broad in scope; the order of presentation does not indicate priority among the recommendations. Identifying children with FASD and co-occurring psychiatric disorders is challenging because the confluence of disorders can easily be missed or misdiagnosed, so treatments for this population have lagged behind. In a perversely reinforcing cycle, the lack of available treatments has also made clinicians reluctant to arrive at a diagnosis of FASD with co-occurring psychiatric disorders. The perniciousness of this problem also calls for a response that embraces research into evidence-based practice, raising awareness among health care providers at all levels, preventing drinking during pregnancy, implementation of evidence-based treatments, training in addressing the behavioral needs of children with FASD and co-occurring psychiatric disorders, and enhanced leadership at all points of the health care system that affect this population.

## **Research**

Studies should be conducted in the following areas:

- The effects of alterations in child behavior on the mother–child relationship for individuals with FASD (O'Connor & Paley, 2009).
- The treatment for preschool-age children to capitalize on early neuroplasticity and the benefits of early diagnosis of serious emotional and mental disorders.
- The unique challenges faced in diagnosing and treating FASD and co-occurring psychiatric disorders in special populations (e.g., American Indians and Alaska Natives).
- Efficacious interventions that can be translated and evaluated in community settings to increase the accessibility of services for children with FASD and co-occurring psychiatric disorders (Paley & O'Connor, 2011).
- Large-scale randomized control trials on the efficacy of stimulants and other classes of medications for children with FASD and psychiatric disorders, including factors that predict treatment response to medications (Paley & O'Connor, 2009).

These studies should be characterized by:

- Large sample sizes to identify how child, family, and system factors may moderate treatment response, including where children fall on the FASD continuum, their profile of neurocognitive deficits, and the presence or absence of comorbid psychiatric conditions.
- Follow-up assessments to show any benefit after interventions have ceased and in less predictable environments than highly controlled research settings.

## **Clinical Awareness**

- Establish training on recognition and treatment of co-occurring psychiatric disorders in those with FASD for professionals who work in high-risk settings, such as substance abuse and addiction treatment centers, orphanages, jails, foster care, and juvenile justice systems.
- Ensure training in diagnosis, treatment, and prevention of FASD and co-occurring disorders to all psychiatry trainees (Eyal & O'Connor, 2011).
- Integrate innovative educational programs on FASD and co-occurring psychiatric disorders into curricula used in medical schools, residency programs, and nursing and allied health training programs.
- Develop, disseminate, and implement evidence-based practices and tools for prevention, diagnosis, and referral of children with FASD and co-occurring psychiatric disorders so that general and subspecialist pediatricians can earn continuing education units.
- Educate and train medical and allied health professionals in the process of taking prenatal histories of teratogen exposure and to recognize the physical and behavioral signs of PAE.
- Educate and train pediatricians, family doctors, and school personnel to include evaluations of children with FASD as part of screening for other learning disorders.

## **Prevention Programs**

- Provide education about the risks of drinking while pregnant in primary and secondary schools and prenatal clinics serving pregnant teenagers (NOFAS, 2006g).

- Provide routine pregnancy screenings in substance abuse treatment programs to new and returning individuals; screen and refer children of women in recovery who may have been exposed to alcohol in pregnancy (NOFAS, 2006d).
- Develop clinically based surveillance programs for the detection and treatment of infants and young children affected by alcohol, including biologically measured abnormalities in fetuses and young babies (Streissguth, 2007).
- Develop interventions aimed at reducing participation in high-risk activities (alcohol and drug use) for teens and young adults, particularly those raised in the foster care system who may be vulnerable when they are no longer in the system or receiving support services (Paley & O'Connor, 2009).

### **Treatment Interventions**

- Develop comprehensive intervention programs that address other risk factors in the environment of children with FASD and co-occurring psychiatric disorders, such as parental substance abuse, parental psychopathology, and interparental conflict.
- Develop interventions that focus on providing resources, education, training, and even direct services to caregivers to maximize their functioning (Paley & O'Connor, 2009).
- Translate evidence-based best practices regarding children with co-occurring psychiatric disorders into more accessible, community-based services.

### **Training**

- Ensure teacher training about the challenges faced by children with FASD and co-occurring psychiatric disorders and access to special education for those with learning disabilities that are associated with FASD.

### **Leadership**

- Develop comprehensive, multilevel, evidence-based approaches to address functional impairments of children with FASD and co-occurring psychiatric disorders. Involving stakeholders at all levels and stages of care will result in streamlining the response,

reducing health care expenditures on this population, and decreasing hospitalizations, especially psychiatric hospitalizations.

Recent studies make clear that co-occurring psychiatric disorders are both over-represented and under-recognized among the population of children with FASD (APA, 2012; O'Connor et al., 2006). There is a consequent lack of research into evidence-based treatments for children with FASD and co-occurring psychiatric disorders, a lack which the present paper throws into stark relief. The small-scale studies on behavioral interventions discussed here and the grant-funded work being done in the Alaska program point the way. But there is a vital need for research into evidence-based interventions to treat children with FASD and co-occurring psychiatric disorders conducted with large populations that can be disseminated to policymakers, researchers, and treatment providers across the country.





## REFERENCES

- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders* (DSM-5). Arlington, VA: Author, 2012. Retrieved from <http://www.dsm5.org/proposedrevision/pages/proposedrevision.aspx?rid=574>
- Ashley, O.S., Marsden, M.E., & Brady, T.M. Effectiveness of substance abuse treatment programming for women: A review. *American Journal of Drug and Alcohol Abuse*, 29(1): 19–53, 2003.
- Astley, S.J., Bailey, D., & Talbot, C. Fetal Alcohol syndrome (FAS) primary prevention through FAS diagnosis, II: A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol & Alcoholism*, 35(5): 509–519, 2000.
- Baer, J.S., Sampson, P.D., Barr, H.M., Connor, P.D., & Streissguth, A.P. A 21-year longitudinal analysis of the effects of prenatal alcohol exposure in young adults drinking. *Archives of General Psychiatry*, 60: 377–385, 2003.
- Bertrand, J. Interventions for children with FASD: Overview of findings from five innovative research projects. *Research in Developmental Disabilities*, 30(5): 986–1006, September 2009.
- Bright Futures. <http://brightfutures.aap.org/>
- Carlson, B. Best practices in the treatment of substance-abusing women in the child welfare system. *Journal of Social Work Practice in the Addictions*, 6(3): 97–115, 2006.  
doi:10.1300/J160v06n03\_08
- Centers for Disease Control and Prevention. *Reducing alcohol-exposed pregnancies: A report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect*. Atlanta, GA: Author, March 2009. Retrieved from <http://www.cdc.gov/ncbddd/fasd/documents/redalcohpreg.pdf>
- Centers for Disease Control and Prevention. *Preventing alcohol use during pregnancy: Project CHOICES*. Atlanta, GA: Author, n.d. Retrieved from <http://www.cdc.gov/ncbddd/fasd/research-preventing.html>
- Centers for Medicare and Medicaid Services. What is a PRTF. Washington, DC: Author, n.d. Retrieved from <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/WhatisaPRTF.pdf>

- de Sanctis, L., Memo, L., Pichini, S., Tarani, L., & Vagnarelli, F. Fetal alcohol syndrome: New perspectives for an ancient and underestimated problem. *Journal of Maternal-Fetal and Neonatal Medicine*, 24(S1): 34–37, 2011.
- Diekman, S.T., Floyd, R.L., & Decouffe, P.A. Survey of OB-GYNs on their patient's alcohol use. *Obstetrics and Gynecology*, 95: 756–763, 2000.
- Disney, E.R., Iacono, W., McGue, M., Tully, E., & Legrand, L. Strengthening the case: Prenatal alcohol exposure is associated with increased risk for conduct disorder. *Pediatrics*, 122(6): e1225–e1230, December 2008.
- Dubovsky, D. Mental Health Disorders in Individuals With FASD: Proper Diagnosis and Treatments. Paper presented at the Alaska Fetal Alcohol Summit, Anchorage, AK, March 2004.
- Eyal, R., & O'Connor, M.J. Psychiatry trainees' training and experience in FASD. *Academic Psychiatry*, 35(4): 238–240, 2011.
- FASD Regional Training Centers Consortium. Educating health professionals about fetal alcohol spectrum disorders. *American Journal of Health Education*, 38(6): 364–373, 2007. Retrieved from <http://www.eric.ed.gov/PDFS/EJ795605.pdf>
- Frankel, F., Paley, B., Marquardt, R., & O'Connor, M. Stimulants, neuroleptics, and children's friendship training for children with fetal alcohol spectrum disorders. *Journal of Child and Adolescent Psychopharmacology*, 16(6): 777–789, December 2006.
- Fryer, S.L., McGhee, C.L., Matt, G.E., Riley, E.P., & Mattson, S.N. Evaluation of psychopathological conditions in children with heavy prenatal alcohol exposure. *Pediatrics*, 119(3): e733–e741, March 2007.
- Gahagan, S., Sharpe, T.T., Brimacombe, M., Fry-Johnson, Y., Levin, R., Mengel, M., et al. Pediatricians' knowledge, training, and experience in the care of children with FAS. *Pediatrics*, 118(3): e657–668, September 2006.
- Hoyme, H.E., May, P.A., Kalberg, W.O., Kodituwakku, P., Gossage, J.P., Trujillo, P.M., et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine criteria. *Pediatrics*, 115(1), 39–47: January 2005.
- Huggins, J.E., Grant, T., O'Malley, K., & Streissguth, A.P. Suicide attempts among adults with FASD: Clinical considerations. *Mental Health Aspects of Development Disabilities*, April 1, 2008.

- Institute of Medicine. *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention and treatment*. Washington, DC: Author, 1996.
- Jacobson, J.L., & Jacobson, S.W. Effects of prenatal alcohol exposure on child development. *Alcohol Health & Research*, 26(4): 282–286, 2002. Retrieved from <http://www.ehd.org/pdf/Effects%20Prenatal%20Exposure.pdf>
- Jones, K.L., Smith, D.W., Ulleland, C.N., & Streissguth, A.P. Pattern of malformation in offspring of chronic alcoholic mothers. *The Lancet*, 1268–1271, June 9, 1973.
- Kerns, K.A., Don, A., Mateer, C.A., & Streissguth, A.P. Cognitive deficits in nonretarded adults with FAS. *Journal of Learning Disability*, 30: 685–693, 1997.
- Malbin, D.V. FASD: What If? Recognizing FASD/Brain-based Conditions and Improving Outcomes. Portland, OR: Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS), 2008.
- May, P.A., & Gossage, J.P. Estimating the prevalence of FASD: A summary. *Alcohol Research & Health*, 25: 159–167, 2001.
- Minnesota Organization on Fetal Alcohol Syndrome. *DSM questions & answers*. St. Paul, MN: Author, 2008. Retrieved from <http://www.mofas.org/wp-content/uploads/2011/03/DSMQA1.pdf>
- National Center on Birth Defects and Developmental Disabilities. *Fetal alcohol syndrome: Guidelines for referral and diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention, 2004.
- National Institute of Mental Health. *Attention deficit hyperactivity disorder among children*. Bethesda, MD: Author, n.d. Retrieved from [http://www.nimh.nih.gov/statistics/1ADHD\\_CHILD.shtml](http://www.nimh.nih.gov/statistics/1ADHD_CHILD.shtml)
- National Institute on Alcohol Abuse and Alcoholism. NIAAA advances research on fetal alcohol spectrum disorders. *NIAAA Spectrum*, 3(3), September 2011. Retrieved from <http://www.spectrum.niaaa.nih.gov/archives/v3i3Sept2011/features/fasd.html>
- National Organization on Fetal Alcohol Syndrome. *Alcohol use during pregnancy: What OB-GYNs should know*. Washington, DC: Author, 2006a. Retrieved from [http://www.nofas.org/wp-content/uploads/2012/05/OB\\_GYN\\_front.pdf](http://www.nofas.org/wp-content/uploads/2012/05/OB_GYN_front.pdf)

- National Organization on Fetal Alcohol Syndrome. *FASD Interventions*. Washington, DC: Author, 2006b. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/intervention.pdf>
- National Organization on Fetal Alcohol Syndrome. *FASD: Treatment and support*. Washington, DC: Author, 2006c. Retrieved from <http://www.nofas.org/treatments-support/>
- National Organization on Fetal Alcohol Syndrome. *FASD: What policy makers should know*. Washington, DC: Author, 2006d. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/policymakers.pdf>
- National Organization on Fetal Alcohol Syndrome. *FASD: What school systems should know about affected students*. Washington, DC: Author, 2006e. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/students-school.pdf>
- National Organization on Fetal Alcohol Syndrome. *FASD: What the foster care system should know*. Washington, DC: Author, 2006f. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/fostercare.pdf>
- National Organization on Fetal Alcohol Syndrome. *FASD: What the substance abuse treatment system should know*. Washington, DC: Author, 2006g. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/substance-abuse-professionals.pdf>
- National Women's Health Resource Center. *Substance abuse*. Red Bank, NJ: Author, 2006. Retrieved from <http://www.healthywomen.org/condition/substance-abuse>
- O'Connor, M.J., McCracken, M.D., & Best, A. Under recognition of prenatal alcohol exposure in a child inpatient psychiatric setting. *Mental Health Aspects of Development Disabilities*, 9(4): 105–109, 2006.
- O'Connor, M.J., & Paley, B. Relationship of prenatal alcohol exposure and the postnatal environment to child depressive symptoms. *Journal of Pediatric Psychology*, 31(1): 50–64, 2006.
- O'Connor, M.J., & Paley, B. Psychiatric conditions associated with prenatal alcohol exposure. *Development Disabilities Research Review*, 15: 225–234, 2009.
- O'Connor, M.J., Shah, B., Whaley, S., Cronin, P., Gunderson, B., & Graham, J. Psychiatric illness in a clinical sample of children with prenatal alcohol exposure. *American Journal of Drug & Alcohol Abuse*, 28: 743–754, 2002.

- Paley, B., & O'Connor, M.J. Intervention for individuals with fetal alcohol spectrum disorders: Treatment approaches and case management. *Development Disabilities Research Review*, 15: 258–267, 2009
- Paley, B., & O'Connor, M.J. Behavioral interventions for children and adolescents with FASD. *Alcohol Research & Health*, 34(1), 2011. Retrieved from <http://pubs.niaaa.nih.gov/publications/arh341/64-75.htm>
- Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention. Grant #R04/CCR008515. Seattle, WA: University of Washington School of Medicine Fetal Alcohol and Drug Unit, 1996.
- Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., & Young, J.K., Risk factors for adverse life outcomes in FAS and FAE. *Journal of Developmental and Behavioral Pediatrics*, 25(4): 228–238, 2004.
- Streissguth, A.P. Offspring effects of prenatal alcohol exposure from birth to 25 years: The Seattle Prospective Longitudinal Study. *Journal of Clinical Psychology in Medical Settings*, 14(2): 81–101, 2007.
- Substance Abuse and Mental Health Services Administration. *Fetal alcohol spectrum disorders: Tips for elementary school teachers*. Rockville, MD: Author, 2004. Retrieved from <http://fasdcenter.samhsa.gov/documents/WYNKTeachersTips2.pdf>
- Substance Abuse and Mental Health Services Administration. *Fetal alcohol spectrum disorders by the numbers*. Rockville, MD: Author, 2006a. Retrieved from [http://fasdcenter.samhsa.gov/documents/WYNK\\_Numbers.pdf](http://fasdcenter.samhsa.gov/documents/WYNK_Numbers.pdf)
- Substance Abuse and Mental Health Services Administration. *How fetal alcohol spectrum disorders co-occur with mental illness*. Rockville, MD: Author, 2006b. Retrieved from [http://fasdcenter.samhsa.gov/documents/WYNK\\_CoOccurMentalIllnes.pdf](http://fasdcenter.samhsa.gov/documents/WYNK_CoOccurMentalIllnes.pdf)
- Substance Abuse and Mental Health Services Administration. *FASD Center for Excellence: Adults*. Rockville, MD: Author, 2010.
- Substance Abuse and Mental Health Services Administration. *Identifying mental health and substance use problems of children and adolescents: A guide for child-serving organizations* (HHS Publication No. SMA 12-4670). Rockville, MD: Author, 2011.

U.S. Department of Health and Human Services. *U.S. Surgeon General releases advisory on alcohol use in pregnancy*. Washington, DC: Author, 2005. Retrieved from <http://www.surgeongeneral.gov/news/2005/02/sg02222005.html>

Walthall, J.C., O'Connor, M.J., & Paley, B. A comparison of psychopathology in children with and without prenatal alcohol exposure. *Mental Health Aspects of Development Disabilities*, 11(3), 2008.

World Health Organization. *International statistical classification of diseases and related health problems*, Version 10. Geneva: Author, 2010. Retrieved from <http://apps.who.int/classifications/icd10/browse/2010/en#/I>

*Prepared by*  
The Disability Service Center JBS International, Inc.

