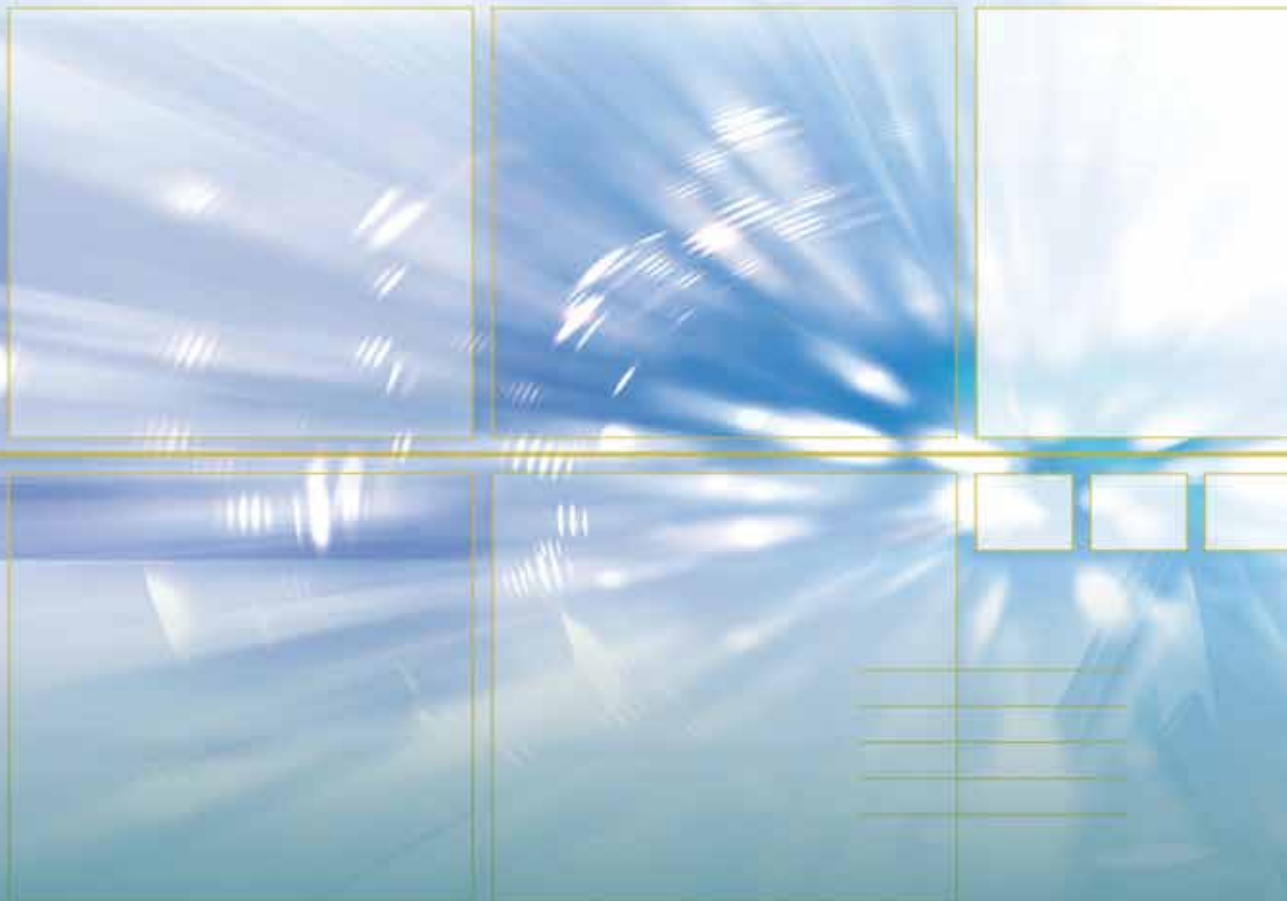




OJJDP Fetal Alcohol Spectrum Disorders Listening Session Report



U.S. Department of Justice
Office of Justice Programs
810 Seventh Street NW.
Washington, DC 20531

Loretta E. Lynch
Attorney General

Karol V. Mason
Assistant Attorney General

Robert L. Listenbee
Administrator
Office of Juvenile Justice and Delinquency Prevention

Office of Justice Programs
Building Solutions • Supporting Communities • Advancing Justice
ojp.gov

Office of Juvenile Justice and Delinquency Prevention
Working for Youth Justice and Safety
ojjdp.gov

The Office of Juvenile Justice and Delinquency Prevention is a component of the Office of Justice Programs, which also includes the Bureau of Justice Assistance; the Bureau of Justice Statistics; the National Institute of Justice; the Office for Victims of Crime; and the Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking.

OJJDP Fetal Alcohol Spectrum Disorders Listening Session Report

		<table border="1"><tr><td></td><td></td></tr><tr><td></td><td></td></tr><tr><td></td><td></td></tr><tr><td></td><td></td></tr><tr><td></td><td></td></tr></table>										

January 2017
NCJ 249202

This report was prepared under contract number 2010C_10031 from the Office of Juvenile Justice and Delinquency Prevention, Office of Justice Programs, U.S. Department of Justice. Points of view or opinions expressed in this document are those of the listening session participants and do not necessarily represent the official position or policies of the U.S. Department of Justice.

Foreword

Fetal alcohol spectrum disorders (FASD) is an umbrella term for a range of disabilities of varying severity that affect youth who were exposed to alcohol during prenatal development. Youth with FASD often have poor social skills, lack impulse control, and have difficulty managing conflict, and they are at increased risk for involvement with the juvenile justice system. There is a clear need to educate legal and judicial professionals about FASD so they can more effectively respond to youth who come into contact with the juvenile justice system. As part of its ongoing commitment to improving life outcomes for youth with FASD, the Office of Juvenile Justice and Delinquency Prevention, in collaboration with the American Bar Association Center on Children and the Law and the Commission on Youth at Risk, organized and hosted a FASD listening session on June 13–14, 2013, in Washington, DC.

At the session, experts from across the nation shared the latest information on diagnosis, treatment, and rehabilitative care as well as perspectives on the courts and the adjudication of youth with FASD. In addition, participants worked to finalize a national action plan with 76 recommendations in a range of areas, including information dissemination, screening and diagnosis, the law and the courts, and the engagement of multiple systems in coordinating the care of FASD-affected youth.

I am confident that the listening session and action plan will chart the course for improved approaches to youth with FASD on the part of our nation's juvenile justice system.

Robert L. Listenbee

Administrator

Office of Juvenile Justice and Delinquency Prevention

Contents

Foreword.....	i
Overview.....	1
Listening Session Day 1—June 13, 2013	5
Welcome and Opening Remarks.....	5
Purpose of the Listening Session	7
An Introduction to FASD.....	7
FASD: Cognitive and Behavioral Dysfunction, Treatment, and Habilitative Care Needs	10
FASD and the Courts.....	15
Interactive Lunch	19
FASD and Delinquent and Nondelinquent Youth: Interactive Discussion.....	20
Introduction to the American Bar Association’s FASD Resolution and Draft Action Plan	22
Listening Session Day 2—June 14, 2013	24
Recap of Day 1.....	24
Morgan Fawcett’s Story: A Champion for Change	25
Live Edit of Draft Action Plan—FASD Recommendations for the Juvenile Justice and Child Welfare Systems.....	26
Closing Remarks	26
Appendix A: Agenda	27
Appendix B: Presenters/Facilitators, Participants, and Observers.....	29
Appendix C: Final Action Plan.....	32
Appendix D: Additional Resources on Evidence-Based Interventions To Address FASD	44

Overview

The Office of Juvenile Justice and Delinquency Prevention (OJJDP) has been a member of the [Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders](#) (ICCFASD) since the late 1990s and currently leads the ICCFASD's [Justice Issues Work Group](#). Created in 1996, the ICCFASD seeks to improve communication and collaboration between agencies to address pressing issues related to fetal alcohol spectrum disorders (FASD), including health, education, developmental disability, research, justice, and social services.

In collaboration with the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the ICCFASD Justice Issues Work Group has worked with the American Bar Association (ABA) [Center on Children and the Law](#), the [National Council of Juvenile and Family Court Judges](#) (NCJFCJ), and other partners to raise awareness about FASD among legal and judicial professionals and begin developing strategies that more effectively meet the needs of individuals affected by FASD.

OJJDP's commitment to addressing FASD and collaborative efforts with the ICCFASD have covered a wide spectrum in recent years, including special informational sessions on FASD at the Office's 2011 National Conference on Children's Justice and Safety; co-funding for the creation of an FASD technical assistance bulletin and an FASD bench guide for judges; and collaboration with the ABA Commission on Youth at Risk and the Center on Children and the Law on a continuing legal education training session on FASD's impact on youth and families and the implications for juvenile, criminal, and child and family law.

In addition, OJJDP, the Center on Children and the Law, and the Commission on Youth at Risk organized an FASD listening session on June 13–14, 2013, in Washington, DC. The session, summarized in this report, served to:

- Raise awareness about the impact of FASD on those involved in juvenile delinquency, status offender, and dependency proceedings and the probation, detention, and corrections systems.
- Highlight the need for FASD education and training to judicial, legal, and juvenile justice professionals.
- Address how government agencies and private organizations with expertise in FASD can best reach these and other constituencies to effectively engage them in training.
- Through such training, identify how to foster changes in the system that will result in reduced recidivism and improved life outcomes for those with FASD.

In preparation for the listening session, OJJDP worked closely with the Center on Children and the Law and the FASD Legal Issues Resource Center to create the agenda, including developing content and identifying presenters and participants. The agenda may be found in appendix A. A full list of participants, facilitators, presenters, and observers and their respective agencies and organizations is presented in appendix B.

On Day 1 of the session, experts in the fields of medicine, psychology, and the juvenile court and juvenile justice systems made presentations on a range of topics, including the effects of prenatal alcohol exposure on the developing brain, diagnostic criteria, treatment and supportive services to address FASD, and the importance of educating youth-serving professionals to ensure the best possible outcomes for youth who have FASD. Following are some highlights of the information and perspectives shared:

- Research has proven that prenatal alcohol exposure can cause significant physical, cognitive, and behavioral impairments. Physical challenges can include growth delays as well as hearing, vision, dental, cardiac, and motor impairments; cognitive challenges can include memory, visual-spatial, and executive functioning deficits; and behavioral challenges can include difficulties with impulse control and managing conflict, and in developing adaptive social skills and independent living skills. There is no cure for FASD, and the challenges associated with these disorders follow youth into adulthood.
- FASD encompasses a range of conditions, including fetal alcohol syndrome (FAS), partial FAS (PFAS), alcohol related neurodevelopmental disorder (ARND), alcohol related birth defects (ARBD), and neurobehavioral disorder associated with prenatal alcohol exposed (ND–PAE).
- Early intervention and treatment services can improve a child’s developmental outcomes. Strategies include medication for some symptoms, behavioral and educational therapies, special education, social services, and the support of a nurturing and loving environment.
- On account of cognitive and behavioral deficits, youth with FASD are at high risk of committing an offense that brings them into contact with the juvenile justice system. Even though a substantial percentage of youth with FASD get into trouble with the law, these disorders are seldom suspected or recognized, even when youth with FASD chronically behave inappropriately.

- All individuals who make decisions in juvenile cases (including caseworkers, police, prosecutors, judges, and probation and parole officers) should be trained on the effects of prenatal alcohol exposure and the physical and behavioral characteristics that are associated with all of the medical and mental health conditions (diagnoses) that are considered to be in the FASD spectrum. Such training is critical to an effective response to the needs of these youth and to ensuring that their rights are protected when they come into contact with the juvenile justice system.
- The disorders in the FASD spectrum should be mitigating factors in adjudication and sentencing because these disorders arise from circumstances entirely beyond the control of individuals with FASD and affect young persons' abilities to understand society's norms and to conduct their behavior within those norms.

Also on Day 1, Howard Davidson of the ABA Center on Children and the Law and Kathryn Kelly of the FASD Legal Issues Resource Center presented a draft action plan that outlined, as a preliminary document for the participants, how both individually and collectively they might best serve youth with FASD and their families who become involved in the juvenile and family court systems. The draft plan was provided to participants before the listening session for their review so that they would be prepared to edit it and later produce a final version.

At the beginning of Day 2, Ira Chasnoff, MD, offered a brief review of the scientific, biomedical, clinical, and judicial presentations of the previous day. Dr. Chasnoff emphasized that the brain damage caused by prenatal alcohol exposure results in mild to severe deficits in neurocognitive functioning, adaptive functioning, and self-regulation. Dr. Chasnoff also reviewed diagnosis of the medical and mental health conditions in the FASD spectrum and data demonstrating that the postnatal environment interacts with the prenatal alcohol-induced brain injury to mitigate or exacerbate functional outcomes. In addition, Dr. Chasnoff summarized how impairments seen in children, youth, and adults with FASD present challenges for individuals and families affected by FASD when they come into contact with the courts but also present challenges for the judiciary.

Later on Day 2, listening session participants discussed and made suggestions for revising the ABA's draft action plan document; in the weeks following the conclusion of the listening session, participants worked together to finalize the action plan, presented in appendix C. The plan contains 76 recommendations for action.

Also on Day 2, Morgan Fawcett, a young Alaska Native who organizes benefits and concerts across the country to raise awareness about and advocate for youth with FASD, shared his own experiences with FASD. In 2011, Fawcett and 10 other American Indian and Alaska Native youth leaders were honored at the White House as Champions of Change. These youth were recognized for innovative programs that help their communities and disseminate information about important issues impacting tribal youth.

Listening Session Day 1—June 13, 2013

Welcome and Opening Remarks

Robert L. Listenbee, Administrator, OJJDP

Robert L. Listenbee, Administrator of OJJDP, opened the session by asking Melodee Hanes, then-Principal Deputy and former Acting Administrator of OJJDP, to share her experiences as a prosecutor handling cases of youth with FASD. Ms. Hanes told of a case she had prosecuted in Des Moines, IA, involving an 18-year-old man charged with raping a 14-year-old girl. Experts brought into the case determined that this young man suffered from a medical disorder that is in the FASD spectrum of adverse conditions associated with prenatal alcohol exposure. His hallmark behavior included confessing to the crime, all the while not seeming to understand what the consequences were. All parties involved—the judge, the public defender, and Ms. Hanes as prosecutor—accepted the experts’ opinion that this young man did indeed have a medical or mental health condition considered to be in the FASD spectrum but, unfortunately, there was no alternative sentence for him in the justice system. They were all concerned that the sentence they were mandated to give him—time in prison—would be detrimental to him. While incarcerated, he would never receive proper treatment or care for a condition he acquired through no fault of his own. Eventually they found an alternative for the young man, but it was like “moving mountains” to accomplish this, Ms. Hanes said.

Mr. Listenbee continued the opening remarks by highlighting OJJDP’s vision:

OJJDP envisions a nation where our children are healthy, educated, and free from violence. If they come into contact with the juvenile justice system, the contact should be rare, fair, and beneficial to them.

Among the youth who are often at risk of entering the juvenile justice system are youth with FASD. Youth with FASD can have serious learning disabilities, motor function delays, cognitive and executive functioning deficits, and poor social skills. However, many of these problems can be lessened by early and correct diagnosis and early intervention. There are a range of available therapies: special education services, speech and occupational therapy, child and family therapy, and other supports.

Because youth with FASD often have poor social skills and lack impulse control, this can lead to rejection from peer groups and association with other socially isolated youth—which increases the risk of delinquent behavior.

When youth with FASD end up in court, their disorders often go unrecognized. Although a few juvenile court judges have helped their courts identify and aid youth with FASD, standard juvenile justice interventions currently do not take FASD-related disabilities into account.

Mr. Listenbee said it is important for legal, judicial, and juvenile justice professionals to be informed about the factors that predispose these youth to come into contact with the justice system and how to effectively represent these youth in court.

OJJDP is a member of the [Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders](#) (ICCFASD) and has worked with many other groups, including the ABA Center on Children and the Law and the National Council of Juvenile and Family Court Judges (NCJFCJ), to develop strategies that more effectively meet the needs of individuals affected by FASD.

Mr. Listenbee provided examples of OJJDP's collaborative activities:

- At OJJDP's October 2011 National Conference for Children's Justice and Safety, the Justice Issues Work Group of the ICCFASD offered sessions on the legal and health-related implications of FASD, the impact of maternal alcohol use during pregnancy on newborns, and implications for the welfare of youth with all types of FASD in the juvenile justice system.
- OJJDP awarded a \$30,000 grant in fiscal year (FY) 2012 to NCJFCJ to conduct a survey of the judiciary, in collaboration with the OJJDP-led Justice Issues Work Group, to identify needs related to FASD in the courtroom, develop a [technical assistance bulletin](#)¹ based on the survey results, and work with judges to create a [bench guide](#)² to raise awareness about and address the issues related to FASD. The National Institute on Alcohol Abuse and Alcoholism matched that award in FY 2013.
- At the ABA's midyear meeting in February 2012, the ICCFASD Justice Issues Work Group, the Minnesota Organization for Fetal Alcohol Syndrome (MOFAS), OJJDP, the ABA Commission on Youth at Risk, and the Center on Children and the Law offered a 4-hour [continuing legal education training session](#)³ in which medical, law, and justice experts presented information about FASD's impact on the lives of youth and families and the implications for juvenile, criminal, and child and

¹ The bulletin is available at www.ncjfcj.org/fetal-alcohol-spectrum-disorders.

² The bench guide is available at www.ncjfcj.org/FASD-Guide.

³ The program and archived videos of the training session are available at www.niaaa.nih.gov/about-niaaa/our-work/ICCFASD/proceedings/2012.

family law. This session ultimately resulted in the ABA House of Delegates unanimously passing a [resolution](#)⁴ on FASD that urges legal professionals to receive training to better identify and assist children, youth, and adults involved in the justice system who are affected by FASD, and that recommends passage of legislation and adoption of policies at all levels of government to address its effects and provide better assistance.

Mr. Listenbee requested that the listening session attendees share their expertise and concerns about FASD with each other so that OJJDP could develop a plan on how to best communicate, on a national level, the facts about individuals with FASD, their families, and the professionals who work with them.

Purpose of the Listening Session

Lyman Legters, Fellow, Casey Family Programs, OJJDP

Mr. Legters set out the goals of the listening session, which were—

- To develop recommendations to be incorporated into a final action plan.
- To prepare a summary report on the content of the listening session to inform the field.
- To determine how best to deliver information and tools to the field that help improve the lives of individuals and families who are impacted by FASD.

An Introduction to FASD

Edward P. Riley, Director, Center for Behavioral Teratology, San Diego State University

Dr. Riley explained how a mother's alcohol consumption affects the developing embryo and fetus: When a mother drinks during pregnancy, her blood alcohol level rises and alcohol freely crosses the placenta, resulting in the exposure of the developing embryo/fetus to approximately the same blood alcohol level as the mother. This exposure can lead to the child being born with any of the outcomes that fall under the spectrum of disorders resulting from fetal alcohol exposure.

Dr. Riley provided the history and background on FASD, beginning in the 1970s with the publication of the clinical manifestations of fetal alcohol syndrome (FAS). These include evidence of central nervous system dysfunction, including microcephaly and cognitive-behavioral problems; prenatal and/or postnatal growth deficiency; and a specific pattern of facial features—short palpebral fissures (eye openings), indistinct philtrum (a smooth, flat area between the nose and mouth), and a thin upper lip.

⁴ The resolution is available at www.americanbar.org/groups/child_law/tools_to_use/attorneys/fasd-resolution.html.

In the years of followup research studies and the accumulation of more clinical data, it became clear that prenatal alcohol exposure often resulted in brain damage unaccompanied by the facial features seen in the classic cases of FAS. In 1996, an expert panel under the auspices of the Institute of Medicine of the National Academy of Science (IOM) defined several medical disorders caused by prenatal alcohol exposure. The common characteristic of these disorders is prenatal alcohol-induced brain damage resulting in complex patterns of cognitive and/or behavioral impairments. The term “fetal alcohol spectrum disorders” (FASD) was later introduced as an umbrella term to describe all of the known possible outcomes that can result from alcohol exposure during pregnancy.

FASD is *not* a diagnosis; however, under the umbrella of FASD, the following medical conditions or subtypes exist:

- Fetal alcohol syndrome (FAS) (as described above): Central nervous system dysfunction, characteristic facial features, and growth retardation.
- Partial FAS (pFAS): Central nervous system dysfunction, some but not all three facial features, or absence of growth deficits.
- Alcohol-related neurodevelopmental disorder (ARND): Central nervous system dysfunction, but no abnormal facial features or growth deficits.
- Alcohol-related birth defects (ARBD): Structural anomalies (e.g., cardiac, renal, auditory, ocular, skeletal); these structural defects due to prenatal alcohol exposure are rarely seen alone; rather, they usually co-occur with FAS and pFAS.

In addition to the medical conditions considered under the FASD “umbrella,” FASD also includes the new FASD-relevant mental health disorder, neurobehavioral disorder associated with prenatal alcohol exposed (ND–PAE). This disorder was recently included as a condition in need of further study in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

FAS was the first type of FASD discovered, and, because of its characteristic facial features, is the easiest to diagnose. Therefore, there are more data on FAS than the other types of FASD. All forms of FASD exist wherever alcohol is consumed.

The rates of occurrence of FAS and FASD vary worldwide; it is reported that South Africa has the highest rates of FAS, with 80–90 cases for every 1,000 live births, whereas in the U.S. the estimated rate of FAS is 2 per 1,000 live births. The estimated U.S. rate of all forms of FASD combined (2–5 percent among

young school-age children) are comparable to rates of other developmental disorders, such as those for autism and for attention deficit hyperactivity disorder.

Dr. Riley also described how prenatal exposure to alcohol can affect the developing brain. Alcohol exposure can cause, among other things, cell death, abnormal cell migration, and the reduction in size or complete absence of certain brain structures. As shown in the following chart, alcohol affects many parts of the brain, causing widespread and permanent changes that result in cognitive and behavioral dysfunction.

Brain Changes	Cognitive and Behavioral Dysfunction
<ul style="list-style-type: none"> • Global brain • Cerebral cortex • Corpus callosum • Cerebellum • Hippocampus • Basal ganglia • White and gray matter development 	<ul style="list-style-type: none"> • Intellectual development • Executive functioning • Learning and memory • Visual-spatial processing • Language • Motor function • Attention and hyperactivity • Emotional regulation • Social cognition

Individuals with FAS have been reported to have average IQ levels in the low 70s, whereas those with heavy exposure but without the facial features of FAS have tested in the 80s; however, there is a wide range in both groups. Dr. Riley also noted that the motor functions of children and youth with FAS are impaired, which can lead to a wide range of problems, including poor balance or difficulty with fine motor skills. Executive functions are compromised in individuals with all types of FASD, so they struggle with planning strategies and understanding and applying rules. Any or all of these dysfunctions can lead children and adolescents with FASD to fail in school, develop substance use disorders, and get in trouble with the law.

Dr. Riley believes that early intervention—starting with asking women of childbearing years about their alcohol use—is of paramount importance in reducing the incidence of FASD.

FASD: Cognitive and Behavioral Dysfunction, Treatment, and Habilitative Care Needs

Julie A. Kable, Associate Professor, Department of Psychiatry and Behavioral Sciences, Emory Neuroscience Exposure Clinic, Emory University School of Medicine

Dr. Kable emphasized that a protective environment and the delivery of appropriate services and supports for a child with any medical disorder or mental health condition under the FASD umbrella can increase positive lifetime outcomes. Evidence for this was first summarized by Ann Streissguth in a seminal 1996 report based on data about secondary disabilities from a survey of 451 patients seen at her clinic in Seattle. An abbreviated form of that report was published in 2004.⁵ Since then, evidence that important protective environmental factors improve life outcomes (as first pointed out by Streissguth) has been reported in results from many research and clinical studies in the U.S., Canada, and Western Europe.

Dr. Kable stated that the children with FASD whom she and her staff currently see in her clinics in Georgia experience negative life effects at a higher rate than those in the normal population of the state. These include increased deaths in the family of a child with FASD, depression in the mother, child neglect and/or abandonment, and failure to take part in or use medical and social services. In Dr. Kable's Atlanta clinics, children with confirmed diagnoses of FAS or pFAS have mild, moderate, and sometimes even more severe cognitive impairments (e.g., IQ less than 90).

Dr. Kable stated that much research has shown that children with FASD benefit from protective factors, such as the following:

- Living in a stable, nurturing home for more than 72 percent of their life.
- Being diagnosed before the age of 6 years.
- Never having experienced violence against themselves.
- Staying in a living situation for an average of more than 2.8 years.
- Experiencing a good quality of home life.
- Having applied for and been eligible for developmental disability services.
- Having a diagnosis of FAS (rather than pFAS).

⁵ Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., and Young, J.K. 2004. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics* 25(4):228–238. Available at www.ncbi.nlm.nih.gov/pubmed/15308923.

Children and youth with FASD suffer numerous and widespread physical, cognitive, and behavioral impairments. Individuals with every form of FASD have complex patterns of cognitive and behavioral disorders. Sometimes, they also have physical problems. Each individual with a medical or mental health condition under the FASD umbrella has his/her own unique combination of individual impairments. The following is a sampling of the impairments found in individuals with FASD:

Physical Problems and Treatment Needs

Problem Area	Impairment/Treatment Need
Growth delays	<ul style="list-style-type: none"> • Mostly benign. • Supplementation and/or enteral feedings needed for some.
Hearing	<ul style="list-style-type: none"> • Vulnerability to ear infections, craniofacial malformations, and immune system alterations, resulting in increased visits to pediatrician/ENT. • Hearing impairment and loss—audiology exams.
Vision	<ul style="list-style-type: none"> • Acuity problems; strabismus (cross-eyed); amblyopia (lazy eye). • Increased need for vision exams and visits to ophthalmologist; possible surgical interventions.
Dental	<ul style="list-style-type: none"> • Craniofacial abnormalities create dental crowding. • Teeth need to be pulled; increased need for orthodontic care.
Cardiac	<ul style="list-style-type: none"> • Benign heart murmurs common, but more serious cardiac malformations can occur. • Requires visit to cardiologist and possibly surgeries.
Motor	<ul style="list-style-type: none"> • Delays in gross and fine motor development. • Physical and occupational therapy visits; sometimes, orthopedic care is needed.

Neurocognitive Impairments

Problem Area	Impairments
Memory	<ul style="list-style-type: none"> • Difficulty recalling recently learned information. • Need frequent reminders. • Difficulty retrieving information. • Lose or misplace possessions. • Working memory impairments.
Visual-spatial	<ul style="list-style-type: none"> • Disorganized or poorly planned drawings or constructions. • Perceptions of time, size, distance, or intensity (quantity). • Problems in differentiating left from right. • Problems aligning numbers in columns.
Executive functions	<p>Difficulties with:</p> <ul style="list-style-type: none"> • Regulating basic attention. • Planning and organization. • Mentally manipulating information. • Changing strategies or thinking about things in more than one way. • Abstract reasoning. • Generalizing or applying knowledge to new situations.
Adaptive communication	<ul style="list-style-type: none"> • Impairments often seen in the early acquisition of language. • Impairments in pragmatic or integrative use of language, which involve mental functions that organize semantic and symbolic meaning, grammatical structure, and ideas for purposes of communication.

Behavioral Impairments

Problem Area	Impairments
Dysregulation	<p><i>Early signs</i></p> <ul style="list-style-type: none"> • Greater stress reactivity. • Sleep disruption. • Negative affectivity. <p><i>Later signs</i></p> <ul style="list-style-type: none"> • Externalizing disorders. • Substance use disorders. • Legal difficulties.
Impact on other functioning	<ul style="list-style-type: none"> • Difficulties with reversal shift learning (also called affective shifting), which involves incorporation of feedback during stimulus-reward association. • Coping with negative feedback or failure. • Difficulties with handling overstimulation.
Independent living skills	<p><i>Areas affected</i></p> <ul style="list-style-type: none"> • Basic life skills, such as dressing, toileting, or making change. • Rules of personal safety. • Telling time and organizing daily schedules.
Adaptive social skills	<ul style="list-style-type: none"> • Overly friendly with strangers. • Difficulty reading social cues. • Difficulty understanding social consequences or using social problem-solving skills.

Dr. Kable said parents and caregivers of children and youth with FASD must be educated about the brain damage associated with prenatal alcohol exposure and be trained on how to implement and provide youth access to appropriate supports, including—

- Cognitive habilitation.
- Therapy to address issues such as the effect of disruptive placement.
- Psychiatric care.
- Psychoeducational assessments to create a learning profile.
- Individual speech and occupational therapy.
- Tutoring services.
- Partnering with the schools and advocating for youth affected by FASD.
- Special education services, social supports, and systems with links to community resources.
- Requesting student support team meetings.

Many research-based, validated interventions⁶ for individuals with FASD have been developed and are being implemented in many communities in the United States and Canada. These interventions have targeted behavioral problems, cognitive and academic skills, and adaptive skills. Dr. Kable presented several examples of intervention work that resulted in positive outcomes for both the children with FASD and their parents or caretakers. Positive effects have been demonstrated in studies utilizing supportive behavioral consultation with parents; socio-cognitive habilitation to improve math skills, language, and literacy; rehearsal training to improve working memory; a computer-based intervention to increase fire and street safety skills; and a manualized, parent-assisted social skills intervention. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is funding additional FASD research projects on the effects of selected nutritional supplements, family support groups, and other behavioral interventions to improve functioning in individuals with FASD.⁷

Dr. Kable also discussed a new program (GoFAR) that she and her colleagues developed and are now testing in a pilot study at her clinic at Emory University. Behavioral and cognitive control are deficits commonly seen in individuals with FASD. By school age, these deficits often present themselves as

⁶ Following are links to sites that are updated regularly with information about new evidence-based interventions: <http://pubs.niaaa.nih.gov/publications/FASDFactsheet/FASDfact.htm>; www.niaaa.nih.gov/research/major-initiatives/fetal-alcohol-spectrum-disorders; www.cdc.gov/ncbddd/fasd/research-intervention.html; www.nofas.org/treatments-support. To access additional sources of information about evidence-based interventions, see appendix D.

⁷ More information is available at <http://pubs.niaaa.nih.gov/publications/FASDFactsheet/FASDfact.htm>.

attention, conduct, and behavior problems. Each of these alone and all of these together interfere with the normal learning process. Placing an emphasis on actively being aware that one is engaged in a stepwise learning process (FAR: “F” Focus/Plan, “A” Act, “R” Reflect) has been shown to be effective in improving behavioral control and educational outcomes in children with FASD. The GoFAR program includes manualized training and drills in FAR that are reinforced by a computer “game” with the goal of improving adaptive functioning and behavior to facilitate and enhance learning.

Dr. Kable stated that if the outcomes for children and youth with a history of prenatal alcohol exposure can be altered as a function of their postnatal environmental experience and exposure to targeted interventions, then there is an increased burden of care associated with parenting a child or youth with FASD. This has to be taken into account in making decisions about who the caregiver is, and what supports should be made available to that child or youth and the parents or caregivers.

FASD and the Courts

The Honorable Susan Shepard Carlson, ICCFASD Justice Issues Work Group

Judge Carlson relayed her experiences with FASD while she was a judicial officer in Hennepin County, MN, during an assignment on the detention calendar, where the most at-risk youth often appear. She reported that, in 1996, the county had conducted a year-long record review of this calendar and found that these youth tended to commit serious offenses and/or engaged in repeated delinquent behavior. The youth had the following characteristics:

- Two-thirds were diagnosed with conduct/oppositional defiant disorder, emotional behavioral disability, or learning disability.
- Twenty-eight percent were borderline IQ or intellectually deficient.
- Fifty percent were victims of physical or sexual abuse.
- Seventy-five percent had family histories of substance abuse, domestic violence, child abuse or neglect, criminal behavior, or mental disabilities.
- Forty percent had a child protective services background.

Judge Carlson found that a substantial number of the youth who appeared before her came from families with significant histories of substance use disorders and had many mental health and behavior problems similar to those identified in the county’s 1996 detention calendar study. She had heard of FASD and began to question whether there might be a connection between this history and possible prenatal exposure causing their mental health and behavior problems.

In doing a literature review on FASD deficits and the risk factors associated with delinquency, she found a strong overlap:

FASD	Delinquency
Cognitive impairments	Poor cognition
Impulsivity	Hyperactivity
Trouble in school	Learning disabled with diagnosis of cognitive dysfunction and attention deficit hyperactivity disorder
Behavior (emotional) problems	Early antisocial behaviors

Judge Carlson cited the book *Ghosts from the Nursery* by Robin Karr-Morse and Meredith S. Wiley, from which she quoted:

“Many experts believe that fetal alcohol exposure, particularly because it may go undetected and go untreated, may well be the single largest factor setting up physical and neurological conditions that predispose American babies to aggressive and violent behavior.”

Judge Carlson indicated that there are no national incidence studies of FASD in the juvenile justice system, and there are no universally accepted screening tools for disorders considered under the FASD umbrella of adverse conditions associated with prenatal alcohol exposure. She noted, however, that research has shown a strong link between youth in child protection who also end up in the juvenile justice system and that OJJDP has done extensive studies on these “crossover” youth.

In her years of experience on the bench, Judge Carlson found that professionals in the juvenile justice system have a general lack of understanding of FASD and the importance of identifying the disability. The existing screening tools that professionals use to assess risk of reoffending do not contain questions regarding prenatal exposure history that could lead to a possible diagnosis within the spectrum of FASD. She noted that judges often rely on psychological evaluations for understanding the mental and behavioral health needs of youth as well as their risk of reoffending, and for making sentencing decisions. However, existing screening tools do not include questions about prenatal alcohol exposure that could help identify persons potentially affected by FASD who would have very specific behavioral and mental health needs.

It was her experience that rarely did psychologists inquire about prenatal alcohol exposure, and their recommendations primarily dealt with the symptoms of the youth’s behavior and not the root cause. Judge Carlson noted that research has shown that youth who commit serious offenses or engage in repeated delinquent behavior need risk assessments to match their particular needs and “what works best is what works best for this kid.” She said that getting a diagnostic assessment for youth with FASD would be consistent with this research and help sort out the disability deficits from other behavior problems and help these youth desist from serious and chronic delinquent behavior.

Judge Carlson provided data from two U.S. juvenile court FASD screening programs, which the Substance Abuse and Mental Health Services Administration’s FASD Center of Excellence funded in two U.S. juvenile courts. The programs used the Center’s FASD Expert Panel Screening Tool along with their own individualized criteria for screening. Following are the results of 4 years of screenings (2008–12):

Screening and Diagnosis Results: 2008–12

Youth	17th Judicial District	Hennepin County
Population screened	Screened adjudicated youth on probation or at presentence investigation.	Screened adjudicated youth who scored positive on the Massachusetts Youth Screening Instrument-2 (MAYSI-2); direct referrals from probation and court.
Number screened	805	170
Number screened positive	202 (25%)	77 (45%)
Number of completed diagnoses	92 (46%)	67 (87%)
Number diagnosed with some diagnosis under the FASD umbrella of disorders	44 (48%)	57 (85%)
	63 (64.4 %) identified with a diagnosable cognitive deficit but, in some cases, no proof of prenatal alcohol exposure.	45 (79%) received services.

The results of the Hennepin County screening led to the implementation of the following for youth diagnosed with disorders considered to be under the FASD umbrella:

- An individual intervention case plan (ICP) based on recommendations from reports provided by the diagnostic team.
- A multidisciplinary team (family, social worker, probation officer, diagnostic evaluator, and therapist) to assist with the ICP.
- Referrals to services specifically based on the needs of the youth and family (school support, individual or family therapy, mentoring, job or life skills coaching, and chemical dependency services).
- Recommendations to the court to fulfill the requirements of the ICP.

Outcomes from Hennepin County's intervention were as follows:

- Seventy-four percent of youth with FASD had no new offenses and no probation violations in the first 6 months; 89 percent had no new probation violations 12 months after implementation of intervention services.
- Ninety-five percent had either no change in placement or were moved to a placement that was equally or more appropriate for their needs, as specified in the diagnostic evaluation report.
- Eighty-three percent showed no or reduced numbers of school suspensions at followup, as compared to baseline.
- One hundred percent showed no school expulsions at followup.
- Sixty-seven percent showed increased school attendance levels.
- Twenty-five percent showed no or reduced numbers of school incident reports at followup, as compared to baseline.

Outcomes from the 17th Judicial District's intervention were as follows:

- Twenty were diagnosed with conditions considered to be under the FASD umbrella, 1–3 years prior to data collection.
- Seventeen (85 percent) successfully completed probation and had no further arrests.⁸
- Three of those who were successful are in long-term residential placement, and one was placed permanently with a relative.

⁸ Baseline recidivism was 50 percent in the first year. Source: Eileen Bisgard, J.D., 17th Judicial District, Colorado.

17th Judicial District findings:

- FASD screening done as a simple step in probation intake can identify many children with FASD.
- Appropriate services following diagnosis can increase youth's success on probation.
- Revoking and reinstating probation can help many youth with FASD.
- Caretakers who accept and work with the diagnosis are key to the success of the youth.

Typical probation modifications in the 17th Judicial District:

- Call and remind about probation appointments and court dates.
- Simplify terms and conditions of probation; make them concrete.
- Use visual reminders.
- Revoke and reinstate probation rather than incarcerating violators.

Judge Carlson said youth with FASD may have significant issues at all levels within the juvenile justice system because of their disability, including:

- Arrest (Miranda warnings).
- Confessions (charging by district attorney, culpability).
- Competence.
- Waiver to adult court, admissions, trial, and testimony.
- Sentencing.

She recommended that professionals receive training on FASD and the range of legal issues associated with it. Along with training, courts should also consider: (1) screening all youth for FASD on entering the juvenile justice system; and, (2) incorporating screening for FASD into existing screening and assessment tools. When universal screening for FASD is not practical or economically feasible, Judge Carlson recommended that youth with "red flags" (e.g., chronic truancy, a family history of chemical dependency, history of child protection involvement, learning disabilities, in foster care or raised in adoptive home) get screened for a possible diagnosis of a spectrum disorder resulting from fetal alcohol exposure.

Interactive Lunch

With OJJDP Administrator Robert L. Listenbee

During the interactive lunch, participants engaged in an informal question-and-answer session with Administrator Listenbee. The discussion yielded the following suggestions for OJJDP work related to FASD:

- Include FASD, along with other disabilities, in the discussion of developmental approaches to juvenile justice reform at the Coordinating Council on Juvenile Justice and Delinquency Prevention’s July 26, 2013, meeting.
- Work more closely with state advisory groups and other organizations/groups to raise public awareness about FASD.
- Create a youth advisory group at OJJDP to promote sustained, long-term participation by youth in policy development and implementation.
- Incorporate a focus on indigent defense—a priority of then-Attorney General Eric H. Holder—into the reauthorization of the Juvenile Justice and Delinquency Prevention Act.

FASD and Delinquent and Nondelinquent Youth: Interactive Discussion

Moderated by Lyman Legters

This session was designed to elicit the thoughts and perspectives of participants on best community practices for addressing FASD; to increase diagnosis of all medical and mental health conditions that comprise FASD; and the Child Abuse Prevention and Treatment Act (CAPTA) and FASD. Following is a summary of participants’ responses.

What Is the Ideal Community Practice for Addressing FASD?

- Multidisciplinary team meetings (police, medical, legal, social services, detention).
- Strong judicial leadership.
- Public advocacy.
- Provision of training, and sharing of evidence-based practices.
- Equal emphasis on training and implementation; action plans are key to successful implementation.
- Coordination of funding between agencies.
- Federal funding directed to state advocacy groups.
- Testimony by youth with FASD at every level of government.
- More collaboration between the courts, government agencies, and national organizations. Examples: OJJDP’s work with NCJFCJ on a bench guide and with the ABA on FASD-related continuing legal education.
- Increased emphasis on the rehabilitative goals of the juvenile justice system.

Diagnosing Disorders in the FASD Spectrum

It is important that every community increase diagnostic capacity for assessment of all of the disorders under the FASD umbrella (FAS, pFAS, ARND, ARBD, and ND-PAE) so that those with impairments can receive proper intervention and services. For example, school systems might use a diagnosis of FASD to formally implement a change in the treatment or method for addressing a child's behavior. In addition, more documented diagnoses in the community would be helpful in raising awareness about FASD. Early diagnosis is imperative. Physicians need to learn how best to question their patients about their drinking behavior and include this information on patient charts. The goal of identifying prenatal alcohol exposure is not to be judgmental of or punitive to the mother but to help her and healthcare providers understand what her child's special needs may be.

Child Abuse Prevention and Treatment Act

The CAPTA reauthorization Act of 2010 modifies previous language for state grant eligibility such that healthcare providers are required to make appropriate referrals of drug-exposed newborns (including those with a diagnosis of FAS or any other disorder under the FASD umbrella) to child protective services (CPS). CAPTA requires that referrals to CPS be made so that a plan for safe care of the child is developed. The federal law does not consider these referrals to be reports of child abuse or neglect. However, some state laws do consider prenatal drug exposure to be child abuse. The challenge that healthcare professionals face in terms of the 2010 revision of CAPTA is that these referrals can lead to removal of the child from the home. Such disruptions in care can exacerbate impairments due to brain damage associated with prenatal alcohol exposure and can negatively impact the functioning of a child further. The risk of a possible referral to CPS can cause mothers to be reticent to admit to using alcohol while pregnant, which hinders diagnosis and intervention.

The National Institutes of Health and the Centers of Disease Control and Prevention encourage all healthcare providers in the U.S. to routinely screen for alcohol use in all of their patients. The goal of these recommendations is to inform all people about the dangers of misusing alcohol and to treat those who have challenges regarding alcohol misuse. Any use of alcohol during pregnancy is a risk to the unborn child. When healthcare providers routinely ask all pregnant women about alcohol use, counsel them about not consuming alcohol during pregnancy, and provide treatment options or refer for treatment when necessary, fewer children will be exposed to alcohol prenatally. In addition, regular screening will reduce the stigma associated with alcohol misuse and increase treatment and recovery. All of these approaches are expected to have a positive effect on the prevention of FASD.

Introduction to the American Bar Association’s FASD Resolution and Draft Action Plan

Howard Davidson, Director, ABA Center on Children and the Law

Kathryn (Kay) Kelly, Project Director, FASD Legal Issues Resource Center, University of Washington Fetal Alcohol and Drug Unit

Ms. Kelly relayed a personal experience in which an advocate contacted her on behalf of a youth who was facing a 16-year prison sentence. Ms. Kelly arranged for an assessment for possible FAS. The resulting positive diagnosis was shared with defense counsel and the prosecutor, who both worked to have the sentence reduced to 4 years. Since being released, the youth has not returned to the justice system and is a professional singer. Had he served his original 16-year sentence, the outcomes for this youth may not have been so positive, Ms. Kelly said. She went on to list several efforts in which the ABA Center on Children and the Law has been involved, including providing training on FASD to court professionals in the juvenile and criminal justice systems.

Howard Davidson shared that he recognized the connection between FAS and delinquent behavior when he was a juvenile defender in the 1970s. He realized that no one at that time was asking about neurocognitive disabilities and how they would affect the behavior of youth who were in the juvenile justice system. In 2011, Mr. Davidson was invited to make a presentation before the ICCFASD Justice Issues Work Group to discuss how the ABA might help raise national awareness about FASD. In October 2011, Mr. Davidson participated with members of the work group in a plenary session on FASD at OJJDP’s [National Conference for Children's Justice and Safety](#).

Mr. Davidson’s 2011 meeting with the work group resulted in the collaborative development of a Continuing Legal Education (CLE) Program on FASD, which was first presented in a half-day training at the ABA midyear meeting in February 2012.⁹ This CLE session was a collaboration between the work group (led by OJJDP staff), the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS), and the ABA in the critical development of the program. It was funded primarily by NIAAA through the ICCFASD Justice Issues Work Group and by MOFAS.

⁹ The program and archived videos of the training session are available at www.niaaa.nih.gov/about-niaaa/our-work/ICCFASD/proceedings/2012.

At that CLE session, Mr. Davidson introduced a draft of the ABA’s soon-to-be-proposed FASD [resolution](#).¹⁰ The ABA House of Delegates passed the resolution unanimously in August 2012. The resolution noted the challenges faced by defendants with FASD. These challenges include:

- No assessment at all.
- Difficulty in obtaining an assessment.
- Difficulty in convincing judicial officials that the results of the assessment are legitimate.
- Difficulty in developing an appropriate strategy, based on the assessment, to deal with the youth.

The ABA resolution urges attorneys and judges; state, local, and specialty bar associations; and law school clinical programs to help identify and respond effectively to FASD. The resolution calls for training to enhance awareness of FASD and its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems. It also emphasizes the value of collaboration with medical, mental health, and disability experts.

The ABA resolution became the foundation for the draft action plan that Ms. Kelly and Mr. Davidson prepared for this listening session. The draft was provided to all participants before the listening session. Before adjourning at the end of Day 1, participants were asked to review the plan and come prepared on Day 2 with questions, comments, additions, and revisions. A copy of the final plan, which includes 76 action steps, may be found in appendix C.

¹⁰ The resolution is available at www.americanbar.org/groups/child_law/tools_to_use/attorneys/fasd-resolution.html

Listening Session Day 2—June 14, 2013

Recap of Day 1

Ira Chasnoff, M.D., President, Children’s Research Triangle

Dr. Chasnoff provided a recap of the formal presentations and information shared in discussions on Day 1 (See also “Overview” section at the beginning of this report). Following is a summary of Dr. Chasnoff’s remarks.

Effects of Prenatal Alcohol Exposure

Prenatal alcohol exposure affects the structure and functioning of the developing fetal brain. These changes have a significant impact on information processing. There are three general areas that FASD appears to specifically affect: neurocognitive functioning, adaptive functioning, and self-regulation. Environmental traumas (disruptions in placement, abuse, and neglect) will further affect the biological disorders that have resulted from prenatal alcohol exposure. These can increase the likelihood of other mental health disorders co-occurring in individuals with FASD.

Diagnostic Criteria

FASD is an umbrella term referring to a range of adverse medical and mental health conditions that can occur in an individual exposed to alcohol during prenatal development. The effects of the prenatal alcohol exposure include physical, behavioral, mental, and cognitive deficits or learning disabilities, with lifelong implications. Dr. Chasnoff described the medical diagnoses of FAS, pFAS, ARND, ARBD, and the newly identified mental health disorder, ND-PAE, previously described by Dr. Riley on Day 1. He invited the session participants to ask questions about anything that needed further clarification.

FASD, the Courts, and Adjudication

The courts are not prepared to address the needs of children and youth with FASD. However, the disorders in the FASD spectrum should be mitigating factors in adjudication and sentencing because the disorders—

- Are brain based.
- Arise from circumstances entirely beyond the individual’s control.
- Affect the defendant’s ability to understand society’s norms and conduct his or her behavior within those norms.

Research has proven that prenatal alcohol exposure produces organic brain damage that, in turn, results in lifelong deficits in information processing—specifically, neurocognitive functioning, adaptive

functioning, and self-regulation. These are deficits that can lead a child to commit an offense without really understanding the implications of his or her actions—an offense that brings children into the juvenile justice system. Many youth with FASD effects find themselves in both the protective services and the juvenile detention systems.

Morgan Fawcett’s Story: A Champion of Change

Morgan Fawcett and Sue Hempel

In 2011, the White House selected Morgan Fawcett, a young Alaska Native, as a Champion of Change. Morgan’s experiences include multiple medical diagnoses considered under the FASD umbrella of adverse conditions resulting from prenatal alcohol exposure. He was recognized for his national advocacy efforts on behalf of individuals affected by disorders in the FASD spectrum. A musician, Morgan has organized numerous concerts and other events to raise awareness about the needs of youth with FASD.

Morgan shared his own experience. According to Morgan, his mother drank 90–100 days during her pregnancy with him. As a result, Morgan was born with many birth defects, including spina bifida, a cleft palate, vision and heart problems, and has the general cognitive skills of a 4-year-old and difficulty with short-term memory. He struggled initially in school but was able to provide verbal feedback to his caretakers and teachers as to what interventions worked for him. Morgan shared that his siblings also experienced prenatal exposure to alcohol. He and his siblings are the fourth generation in their family to experience FAS and other forms of FASD.

Morgan agreed that adaptations to the juvenile justice system need to be made for youth with FAS and other forms of FASD. Youth within and outside the justice system need constant supervision and access to one-on-one care. Morgan spoke of the program in which he will participate when he attends college in Durango, CO. He will reside in a house with other Native American students, some of whom may have FAS, other forms of FASD, or other disabilities. His grandmother, Sue Hempel, will oversee the operation of the house. The residents will work as a community, both to study and to maintain the house. Living in this house will allow the students to develop and practice life skills while receiving supervision and care.

Morgan said that programs such as this community-living situation can and should be created on a local level. Currently, it is difficult to create and implement programs for those with FASD on a broad level, so



community-based projects can be used as a way to begin addressing the issues surrounding FASD. In the United States, only Alaska has legislation that will use a diagnosis of some type of FASD as a mitigating factor when dealing with those in the criminal justice system.

Live Edit of Draft Action Plan—

FASD Recommendations for the Juvenile Justice and Child Welfare Systems

Moderated by Lyman Legters

The format of this segment of the listening session was adapted in response to participants' interest in having more time to review the plan before the development of a final version. A detailed discussion ensued, with many recommendations for possible revisions to the draft document. Participants also volunteered to become part of special working groups, each group focused on a different section of the plan, and to review and rewrite the plan's sections as needed. Each group agreed to meet by conference call to complete the revisions in the weeks following the listening session. The revisions were incorporated into the final action plan, which is presented in appendix C.

The plan's 76 recommendations emphasize the importance of supporting and offering educational opportunities for legal and court professionals that broaden awareness of FASD and promote collaboration with medical, mental health, and FASD disability experts. The plan also emphasizes the need for ready access to diagnosis, specialized services, and supports to prevent recidivism and promote positive lifetime outcomes for youth affected by FASD.

Closing Remarks

Lyman Legters

Mr. Legters stated that the timing is right for raising awareness about and taking nationwide action to address FASD. The current focus on trauma-informed practice in juvenile justice invites the unique approaches to intervention that youth whose impairments fall under the umbrella of FASD need. OJJDP is committed to both reforming policy and informing the field and the public about FASD. Mr. Legters left the attendees with two action items to consider:

- **Articulate the long-term cost/benefits of intervention and implementation of programs and services.** During this time of budget cuts, presenting a good return on investment can be a way to attract funding.
- **Focus on systems alignment and implementation across disciplines.** Training and public awareness initiatives are effective tools, but they have to take place within a multidisciplinary and cross-systems framework to effect sustained and comprehensive change.

Appendix A. Agenda

Fetal Alcohol Spectrum Disorders: Children and Youth in the Justice System An OJJDP Listening Session

Thursday, June 13, 2013

- 9:00 a.m. **Welcome and Introductions**
Meeting Call to Order: Karen J. Bachar, State Program Manager, OJJDP
Robert L. Listenbee, Administrator, OJJDP
- 9:15 a.m. **Purpose of the Listening Session**
Lyman Legters, Casey Family Programs, Former OJJDP Fellow
- 9:30 a.m. **An Introduction to FASD**
Edward P. Riley, Director, Center for Behavioral Teratology,
San Diego State University
- 10:15 a.m. Break
- 10:30 a.m. **FASD: Treatment and Habilitative Care Needs**
Julie A. Kable, Associate Professor, Department of Psychiatry and
Behavioral Sciences, Emory Neurodevelopment Exposure Clinic,
Emory University School of Medicine
- 11:15 a.m. **FASD and the Courts**
The Honorable Susan Carlson, Interagency Coordinating Committee on Fetal Alcohol
Spectrum Disorders, Justice Issues Work Group (ICCFASD–JIWG)
and the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
- 11:45 a.m. **Interactive Lunch With OJJDP Administrator**
- 1:15 p.m. **FASD and Youth in the Juvenile Justice System (Interactive Discussion)**
Karen J. Bachar
- 2:15 p.m. Break
- 2:30 p.m. **FASD and Delinquent and Nondelinquent Youth (Interactive Discussion)**
Lyman Legters
- 3:30 p.m. **Introduction to the ABA Resolution and Draft Action Plan**
Howard Davidson, Director, ABA Center on Children and the Law
Kathryn (Kay) Kelly, Project Director, FASD Legal Resource Center,
University of Washington Fetal Alcohol and Drug Unit
- 4:15 p.m. **Participant Feedback (open discussion about the day’s topics)**
Lyman Legters
- 4:45 p.m. **Wrap-Up and Goals for Day 2**
Karen J. Bachar

Friday, June 14, 2013

- 8:15 a.m. **Welcome to Day 2**
Lyman Legters, Former Fellow, Casey Family Programs, OJJDP
- 8:20 a.m. **Overview of Day 1**
Ira Chasnoff, President, Children’s Research Triangle
- 8:30 a.m. **Morgan Fawcett’s Story: A Champion of Change**
Morgan Fawcett and Sue Hempel
- 9:00 a.m. **Review and Live Edit of Draft Action Plan—FASD Recommendations
for the Juvenile Justice and Child Welfare System (Interactive Discussion)**
Lyman Legters/Karen J. Bachar
- 10:15 a.m. Break
- 10: 30 a.m. **Next Steps: Moving Forward Together (Interactive Discussion)**
Lyman Legters
- 12:00 p.m. **Closing**
Lyman Legters

Appendix B. Presenters/Facilitators, Participants, and Observers

Titles and affiliations of the individuals on this list are current as of June 13, 2013.

Presenters/Facilitators

Karen J. Bachar

Office of Justice Programs
Office of Juvenile Justice and Delinquency
Prevention

Susan Carlson

Judicial Officer (semi-retired)
4th Judicial District Court Hennepin County,
MN

Ira Chasnoff, M.D.

President
Children's Research Triangle

Howard Davidson

Director
American Bar Association Center on
Children and the Law

Morgan Redmon Fawcett

FASD Self-Advocate

Melodee Hanes

Then-Acting Principal Deputy Administrator
Office of Justice Programs
Office of Juvenile Justice and Delinquency
Prevention

Julie A. Kable

Assistant Director of the Emory
Neurodevelopmental
Exposure Clinic/FAS Clinic
Assistant Professor
Department of Psychiatry and Behavioral
Sciences
Emory University School of Medicine

Kathryn Kelly

Project Director
FASD Legal Issues Resource Center
University of Washington Fetal Alcohol
and Drug Unit
School of Medicine

Lyman Legters

Casey Family Programs

Robert L. Listenbee

Administrator
Office of Juvenile Justice and Delinquency
Prevention

**Management Solutions Consulting Group,
Inc.**

Edward Riley

Director
Center for Behavioral Teratology
San Diego State University

Participants

Melissa Bahmer

Director
Child Abuse and Neglect
National Council of Juvenile and Family Court
Judges

Crystal L. Banks

Deputy Director
Judicial Education and the Center for Education
and Training
District of Columbia Courts
National Association of State Judicial Educators

Elizabeth Bartholet

Faculty Director
Child Advocacy Program
Harvard Law School

Sarah Bergen

Staff Attorney
National Juvenile Defender Center

Susan Broderick

Project Director
Georgetown University's Public Policy Institute
Center for Juvenile Justice Reform

Ed Burnette

Vice President
Defender Legal Services
National Legal Aid & Defender Association

Peter Cohen

Member, Substance Abuse and Addiction
Committee
American Academy of Child and Adolescent
Psychiatry

Tom Donaldson

President
National Organization on Fetal Alcohol
Syndrome

Ernestine S. Gray

Presiding Judge
Orleans Parish Juvenile Court, Sec. A

Lucy Hudson

Director
Safe Babies Court Teams Project
Zero to Three

Carole Hurley

Administrative Law Judge
Texas Health and Human Services Commission

Linda Logan

Tribal Liaison
National Child Protection Training Center
National Center for Prosecution of Child Abuse

Kendall Marlowe

Executive Director
National Association of Counsel for Children

Kamilah Oni Martin-Proctor

National Council on Disability

William Missouri

Judge
Circuit Court, 7th Judicial Circuit

Anne Nelsen

Member and Past Chair, Executive Board
Juvenile Corrections/Detention Facilities
National Partnership for Juvenile Services

Carol Perry

Judge
Navajo Nation
Window Rock Judicial Court

Angela Russell

Associate Judge
Member of the Steering Committee of the
National American Indian Court Judges
Association

Harvey Schweitzer

Attorney at Law
American Academy of Adoption Attorneys

Suzanna Tiapula

Director
National Center for Prosecution of Child Abuse
National District Attorneys Association

Kenneth Warren

Acting Director
National Institute on Alcohol Abuse and
Alcoholism
National Institutes of Health

Saunie Wilson

Judge/President
Native American Children's Alliance Board

Kelli Wynn

Community Supervision Officer
American Probation and Parole Association
Court Services and Offender Supervision
Agency

Barbara Wybrecht

FAS Clinical Nurse Specialist
Spectrum Health

Observers

Sally M. Anderson

Coordinator and Executive Secretary
Interagency Coordinating Committee on
Fetal Alcohol Spectrum Disorders

James Antal

Associate Administrator
Youth Development, Prevention, and Safety
Office of Juvenile Justice and Delinquency
Prevention

Garry Bevel

Staff Director
ABA Commission on Youth at Risk

Deborah Black

Public Health Advisor
Indian Health Services

Megan DesCamps

Legislative Assistant
Office of Senator Tim Johnson (D–SD)

Diane DiSanto

Legislative Assistant
Office of Senator Mark Begich (D–AK)

Jon Dunbar-Cooper

Public Health Analyst
Substance Abuse and Mental Health Services
Administration
Division of Systems Development
Center for Substance Abuse Prevention

Sue Hempel

Morgan Fawcett's grandmother and advocate for
people with FASD

Anna Johnson

Communications Coordinator
Office of Juvenile Justice and Delinquency
Prevention

Eva Klain

Director
Child and Adolescent Health
American Bar Association Center on
Children and the Law

Amanda Makki

Legislative Aide
Office of Senator Lisa Murkowski (R–AK)

Mary Pavel

Staff Director/Chief Counsel
Senate Committee on Indian Affairs
Office of Senator Maria Cantwell (D–WA)

Sarah Pearson

Tribal Fellow
Office of Juvenile Justice and Delinquency
Prevention

Jean Plaschke

Youth Programs Officer
Substance Abuse and Mental Health Services
Administration
Office of Indian Alcohol and Substance Abuse

Margaret Riley

Legal Intern
American Bar Association Center on Children
and the Law

Appendix C. Final Action Plan

Addressing Children and Youth With FASD in the Juvenile Justice and Child Welfare Systems

Introduction

Children and youth affected by prenatal exposure to alcohol comprise a largely unrecognized population coming before the courts. These young people suffer from a range of physical and neurodevelopmental difficulties that fall within the broad definition of Fetal Alcohol Spectrum Disorders (FASD). FASD is an umbrella term used to describe a cluster of medical and psychiatric disorders associated with prenatal alcohol exposure. FASD pose important challenges for lawyers, judges, courts, and other government agencies that deal with the needs of children, youth, and their families. Existing justice-related programs and strategies that may be effective for typically developing children and youth often will be ineffective, and even counterproductive, for those with FASD, primarily because this disability is not readily recognized or understood, so no FASD interventions are provided.

FASD encompass a range of impairments that can occur when the fetus is exposed to alcohol *in utero*. These impairments include structural and functional changes in the developing fetal brain, which can result in developmental delays, significant cognitive problems, learning disorders, and serious behavioral difficulties. Although most individuals with FASD do not have “intellectual disability,” FASD are, nonetheless, the most common preventable cause of intellectual disability.

The most typical neurodevelopmental difficulties present in children and youth exposed to alcohol *in utero* relate to neurocognitive functioning, adaptive behaviors, and self-regulation. These deficits perhaps explain the substantial percentage of individuals with FASD who get in trouble with the law, most often while still juveniles. However, FASD are seldom suspected or recognized, even when children and youth with FASD chronically behave inappropriately. Those suspected of being affected are rarely diagnosed, and sorely needed services are almost never put in place.

Purpose of This Document

This document sets forth a general plan of action for addressing those challenges. It represents a call for commitment that we hope lawyers, judges, social workers, medical and mental health professionals, and others who work in the child welfare and justice systems will respond to in order to better address FASD and their impact on those children and youth that these systems serve.

Improving the Response of the Justice System

Because a substantial number of youth with brain damage from prenatal alcohol exposure (PAE) are involved with the justice system, early recognition of the spectrum of disorders caused by PAE, and referrals for diagnosis, are important steps towards preventing delinquency and recidivism. If a community has not developed the diagnostic capacity needed by the court, then it should be the mission of the justice system to assist in the utilization of existing resources to develop an interdisciplinary team to diagnose all medical and mental health disorders included under the FASD umbrella of adverse conditions resulting from prenatal alcohol exposure.

Youth with FASD require specialized case management during all phases of their involvement with this system (sentencing, corrections practices, case planning, and probation and parole supervision). This must include frequent contact with staff who are attuned to the youth's impairments and can offer the necessary types of in-the-moment assistance (e.g., cues, prompts, reminders) needed for the youth to comply with expectations and conditions.

To the teachers, police, judges, and attorneys involved with their cases, children and youth with FASD seldom appear different from others their age, and their expressive language skills usually do not suggest their underlying cognitive problems. Their speech is deceptively articulate, masking information-processing and receptive communication problems.

The combination of executive and adaptive functioning deficits means that children and youth with FASD often function at the level of someone half their chronological age.

It is essential that juvenile justice, child welfare, family court, education, and social services programs treat children and youth in an age-appropriate manner. The strategies and programs that make sense for a 16-year-old would often be useless for—or even harmful to—an 8-year-old. Therefore, a challenge posed by FASD is that adolescents with this disability give no easily interpreted outward signs that they do not understand much of what is said to them. In stressful situations, they understand even less.

Children's receptive language skills and reading comprehension should be assessed before decisions are made about their ability to sign a confession, agree to a case plan, understand charging documents and probation agreements, serve as an eyewitness, and participate in their own juvenile defense or child welfare case. When someone with this constellation of impairments goes undiagnosed—as is generally

the case—the justice system is going to fail the child, his or her family, and the communities in which they live.

Impact on Children and Youth Involved in the Justice System

It is incumbent on caseworkers, police, prosecutors, judges, probation and parole officers, and others who make decisions in juvenile cases (e.g., petitioning, charging, dispositions, placements, probation, and parole revocation) to be well trained on the impact FASD have on the brain. Such training is necessary to handle these cases in order to protect the rights of the child or youth and allow them to participate in their cases as fully as their disability allows. As is the case with intellectual disabilities generally, FASD should be seen as mitigating factors against transfer from juvenile to adult criminal court. FASD also raise important issues regarding culpability and false confessions. Police, prosecutors, and defense counsel must understand that many of those living with FASD are vulnerable to suggestion in interrogation, leading to the possibility of false confessions and faulty eyewitness recollections.

Judges in juvenile court and in adult courts, who hear cases where a juvenile is transferred for prosecution as an adult, must receive education on FASD and how they affect legal competency and diminished capacity. Those involved in decision making for abused and neglected children also need to better understand how FASD affect removal of children from their homes or placement of children in foster care and other settings. In addition, crime victim services staff, and others who aid children and youth victims of crime, need to understand that individuals with FASD are especially susceptible to victimization (including sexual victimization and exploitation). Thus, these young people will require case management services that provide the safety and structure they need in order to avoid repeated victimization.

FASD are prevalent not only among those involved in juvenile delinquency proceedings but also among parents and children who are involved in child welfare (dependency) court proceedings or juvenile status offender cases. Juvenile status offender cases involve situations where a young person is allegedly acting “beyond the control” of his or her parents (e.g., chronically running away from home, engaging in long-term truancy, using alcohol or drugs, displaying defiant behavior). In these cases, FASD should impact the court’s responses to the issues that result in family dysfunction. Both parent and child may have a type of FASD, and thus diagnosis and management of their impairments must become an important part of case resolution. In particular, parents with FASD will require one-to-one parenting support and ongoing case management to help them successfully manage the tasks of daily living and dealing with their child’s behavioral issues.

When a child with a form of FASD is placed in foster care, the child's substitute caregivers must have education and support to address the child's unique characteristics. The child's caseworker, attorney, guardian ad litem, and court-appointed special advocate (CASA) also need to be prepared to meet the challenges presented by the child's FASD-related impairments. Any changes in routine are especially difficult for children affected by FASD, and every time they have to leave a home and known caregivers, their behavior and emotional stability may worsen.

Therefore, when placing a child, it is important to equip caregivers with the tools they need to avoid placement disruption (e.g., respite care so caretakers can have a regular night out, a night out for the child to give the family a break, assistance with grocery shopping, transportation to and from school to avoid the chaotic experience on the bus). If it seems likely that the caregivers will request a child's removal, the professionals working with the family should assess the situation to ensure that the family has received all the resources needed to properly care for the child before concluding that a placement change is actually necessary.

Another group of children significantly affected by FASD are those who are adopted or are in pre-adoptive placements, both domestically and internationally. Courts hearing termination of parental rights and adoption cases must pay particular attention to the importance of preventing adoption failure by providing appropriate state subsidies and long-term services to support families adopting a child with any type of the FASD. As suggested above with foster care placements, a critically important service for adoptive parents is respite care. It helps to prevent disruption of adoptions and continues to be important even into the adoptee's adulthood.

Supporting Needed Services

For the majority of children and youth who have the most severe impairments associated with FASD, it is essential they have knowledgeable and effective legal advocates to secure appropriate government and insurance disability benefits. FASD are "pre-existing conditions" that insurers should be covering with diagnostic assessments, comprehensive therapeutic services, and medication as required. Preschool and school-age children with FASD may also require Individualized Education Plans under the federal *Individuals with Disabilities Education Act* (IDEA). Therefore, education attorneys must receive training on understanding how FASD affect learning and retention.

For those whose functioning is most seriously affected by FASD, public benefit advocates must understand how to best pursue Social Security disability payments (SSI) for both children and youth. The legal advocates for adult caretakers of those children or youth who have the greatest degree of impairment must also have information on how best to use guardianship, conservatorship, and Social Security representative payee laws to preserve and protect the assets of individuals with FASD, and possibly, as those individuals approach the potential for living independently, the need for vocational and independent living resources.

Improving Government Institutions, Laws, and the Implementation of Laws

Existing laws, both federal and state, address the prevention of harm to those with disabilities and the delivery of early intervention services for them. These laws must be re-examined through the lens of advocacy for those children, youth, and families living with FASD. Federal, state, and local law and policymakers are asked to consider the enactment of laws and the implementation of policies that will reflect and address the serious effects of prenatal alcohol use and its impact on young people while promoting the best interest of children.

However, caution should be exercised in the use of criminal sanctions when considering approaches towards women who consume alcohol during pregnancy. There is a view that criminalization of the behavior of women drinking during pregnancy can result in pregnant women and mothers being driven into the shadows, where they do not seek the care and treatment they require. Instead, government intervention should focus on safe homes for children and supportive services for their families. There is also the view that alcohol use during pregnancy may reflect either irresponsible parenting or a struggle with addiction, either of which might warrant intervention for the safety of the child and for the support of the mother.

Developing and disseminating a model for FASD legislative reform may be one appropriate approach toward statutory improvement. Such “model laws” must address the prevention of alcohol-affected births through general education at all levels and through the education of pregnant women as well as mothers. These laws must also help assure that better FASD data are collected and reported so that the public health surveillance system, and those who are a part of it, can better understand the full incidence of this problem in order to better respond to it.

Other government entities, such as juvenile justice, child welfare, protection and advocacy for those with disabilities, special education, and developmental disability agencies, must have specially trained and designated staff to help assure that laws and policies related to children and youth with FASD are effectively implemented. Particular attention should be paid to implementing the 2010 amendment to the federal *Child Abuse Prevention and Treatment Act* that mandates health professional referrals to child protective services for development of “safe care plans” for infants and newborns diagnosed with FASD. To date, there has been very little implementation of this potentially important tool to help protect those affected by FASD and to encourage mothers whose children are diagnosed with FASD to avoid drinking in future pregnancies.

Foster parents, youth corrections/detention personnel, and group home and residential treatment program directors must become knowledgeable about FASD and how they impact the behaviors of, and risks faced by, those children and youth receiving this care and supervision. Addiction professionals, mental health service providers, social workers, and those providing “wraparound services” must also have this information. Therefore, continuing education programs for these professionals must incorporate the very latest knowledge on FASD and its impact on children, youth, and families.

Educating Attorneys and Judges

There is encouraging information about effective strategies in dealing with this disability in the juvenile court, addiction treatment, family services, education, Social Security, and disability benefit systems. Ample opportunities should be provided, through legal and judicial conferences and continuing legal and judicial education (CLE and CJE) programs, to provide trainings on FASD and their varied impact on children, youth, and families for all stakeholders in juvenile-serving systems, including defense lawyers, prosecutors, judges, and anyone who works within the justice system. The latter group should include probation officers, parole officers, detention staff, service providers, juvenile and child welfare caseworkers, physicians, and culture-specific healers or medicine men within the belief system they operate under, as well as the system-involved parents and youth. Videos and Webinars are available to enable professionals to learn more about this topic.

Those who provide educational opportunities for juvenile defenders, prosecutors, child welfare attorneys, family lawyers, and judges involved with the range of cases involving children and youth must provide adequate training on FASD within those activities. We also encourage the development of a law school curriculum on FASD. This could be used in juvenile justice, children and the law, child advocacy, mental

health and the law, family law, Indian law, and other courses and could be useful to those students working in clinical legal aid programs who encounter a client with any possible or diagnosed disorder under the FASD umbrella. The curricula for educating lawyers, judges, and law students must focus not only on understanding FASD but also on how to best apply that information in the knowledgeable representation of clients with this disability and youth who appear before the court.

What Else Can Be Done?

In a number of states, programs have been implemented that identify children or youth with FASD and utilize programs and strategies adapted to the particular needs and behavioral problems of those individuals. This approach has proven remarkably effective in preventing recidivism among juvenile defendants and in helping those with this disability to function appropriately.

Justice system programs and professionals can take steps calculated to both meet individual youth needs and to intervene effectively in dealing with the problem of FASD. The best specific approach will depend on the nature of each particular program and on the types of resources that may be available.

In general, institutional and individual responses to the challenge of FASD should encompass four distinct elements:

1. Educating professionals who work with children and youth about the nature of FASD and the types of behavioral problems they may cause, through either in-house training or outside programs like continuing legal and judicial training programs.
2. Putting a system in place to screen for individuals who may have this disability and, where not already available in the community, developing a multidisciplinary diagnostic team to assess those who screen positively for any form of FASD.
3. Identifying effective strategies for the specific program/organization/system to deal with children and youth with FASD, including identifying long-term programs or services that a disabled individual may need and for which they may qualify.
4. Developing methods for exchanging ideas and information with other organizations and professionals in the same field who are also attempting to address the problems caused by this disability.

It is not enough to understand and effectively address FASD in the juvenile delinquency, child welfare, status offense, and adoption contexts. Courts and other government agencies must become aware that, with diagnosis, the existence of this disability may render an individual youth eligible for participation in

state developmental disability programs and the federal SSI program. It may also entitle them to individualized education plans under the *Individuals with Disabilities Education Act*.

The problems and issues raised by FASD can best be addressed when a medical diagnosis of this disability can be obtained for an individual. However, when obtaining a diagnosis is impractical for financial or other reasons, reasonable efforts should be made to ascertain whether an individual may have been exposed to alcohol prior to birth and to explore steps that should be taken in light of that information.

The American Bar Association Resolution on FASD, of August 7, 2012, and its accompanying Report provide another useful overview of the issues raised by FASD and an informed analysis of effective responses to the serious problems that children and youth with FASD may have.

Conclusion

Because of the scope of FASD's impact on children and youth, we need to take concrete and meaningful steps to increase awareness of FASD within our professional communities. Attorneys, judges, bar association leaders, law school deans, and directors of other entities involved with at-risk youth, juvenile justice, the child welfare system, and the family courts should support educational opportunities that broaden awareness of FASD within their constituencies. In that process, they should collaborate with medical, mental health, and FASD disability experts to promote, as ABA has encouraged, appropriate legal representation and advocacy for individuals with FASD.

Finally, and most importantly, we want to see better support for efforts which will ensure that individuals with FASD, and specifically children and youth with FASD, have the best possible life outcomes through ready access to both skilled legal representation and an enlightened judiciary. We want to assure that they have readily accessible opportunities for diagnosis and for the specialized services that this disability requires, as well as necessary supports to prevent recidivism and to make full use of their many talents and strengths.

76 Possible Actions To Address the Needs of Those With FASD in Juvenile Justice, Child Welfare, Family Court, and Tribal Court Systems

Organizational Responses

1. Designate an official in your organization who will be responsible for overseeing actions to address FASD.
2. Enact an organizationwide formal policy resolution on FASD.
3. Arrange for inclusion of information about FASD as part of existing training programs or at national, regional, state, or local conferences in (ideally) plenary or breakout sessions.
4. Arrange for in-office staff briefings by experts on FASD.
5. Identify any existing local experts on FASD, such as a state FASD coordinator.
6. Disseminate written information about FASD and the relationship of FASD to your program's work, either electronically (e.g., by email or on your website) or in hard copy (e.g., in handouts or an organization newsletter or magazine).
7. Identify, develop, and attend continuing legal education or similar trainings about FASD and/or FASD-related legal issues.
8. Identify useful FASD websites, organizations, and materials.
9. Identify useful printed or online materials about FASD and the impact of FASD on individuals in your program—and consider how you might make them available to professionals involved with your work as well as accessible to affected youth and their families.
10. Disseminate fact sheets on FASD to aid attorneys, judges, and others in understanding, identifying, and providing accommodation and interventions.
11. Hold stakeholder-specific trainings on FASD.
12. Develop a strategic plan for helping ensure prevention of FASD and timely screening, diagnosis, and treatment for those with FASD.
13. Assess whether any organizational practices now in general use would be likely to be ineffective or counterproductive for individuals with FASD.
14. Identify outside programs or services that could be helpful to individuals with FASD who are in your program, and develop strategies for establishing their eligibility for such programs or services.
15. Identify alternative practices or strategies that might be more effective for individuals with FASD, including obtaining information about steps taken by other programs similar to your own.

16. Identify individuals and programs that have devised screening or programmatic responses to FASD in organizations with a mission similar to your own.
17. Evaluate ways in which FASD might affect the behavior of an individual with whom your program is dealing.
18. Evaluate whether it would be appropriate to use distinctive approaches for individuals who have screened positively for FASD but have not yet been formally diagnosed.
19. Consider whether needed FASD-related programmatic changes require changes in policies, rules, or protocols.
20. Incorporate needed changes related to FASD in relevant office manuals.
21. Consider whether needed FASD-related programmatic changes require new legislation that you could support.

Systemic Responses

Key Nationwide Reforms

22. Develop local, state, and national actions in response to FASD for different professional groups.
23. Find and use a list of FASD resources. [There is a need to update the *Resource Directory for the Diagnosis, Prevention and Treatment of FAS*, written by Barbara Morse, Ph.D., and Corinne Barnwell, M.S.W., and published in 2000 by the Health Resources and Services Administration (HRSA) of HHS.]
24. Develop a national listserv on FASD.
25. Identify experts who can be content witnesses on FASD.

Information and Knowledge Improvement

26. Identify credible sources of information regarding FASD.
27. Access and use resources provided by the Substance Abuse and Mental Health Services Administration's FASD Center for Excellence at www.fasdcenter.samhsa.gov.
28. Create an inventory of what we know about FASD.
29. Develop and disseminate "Ten things that everyone should know about FASD."
30. Address gaps in access to information on FASD.
31. Make sure that FASD fact sheets are in plain, easy-to-understand language.
32. Conduct editorial board meetings with the press to educate them on FASD.
33. Recognize the importance of the youth voice, with their input addressed in FASD training and in the development of relevant resources.
34. Conduct briefings with legislative leaders and policymakers to introduce them to FASD.

35. Identify public and private partnerships and develop, legislatively, a blueprint for funding FASD programs on a national level.
36. Address the importance of extended family input in addressing FASD.
37. Publicly honor the period of pregnancy to produce safe, healthy babies, free of FASD (use of a special ceremony, etc.).

Screening and Diagnosis Improvement

38. Examine existing screening tools and determine how to incorporate a question on prenatal alcohol exposure into these evaluative instruments.
39. Support research into a valid screening methodology to identify potential cases of FASD.
40. Identify local medical experts and diagnostic teams who can diagnose all forms of FASD.
41. Identify professionals who can conduct appropriate treatment plans for individuals with FASD.
42. Establish multidisciplinary teams who can diagnose all forms of FASD.
43. Use multidisciplinary teams and Children’s Advocacy Centers to help identify and effectively serve children affected by FASD.
44. Increase the number of relevant diagnostic clinics available in every state.
45. Make professionals aware of online diagnostic training for FASD, and direct observation from the FAS Diagnostic and Prevention Network (FAS–DPN) at the University of Washington, <http://depts.washington.edu/FASDPN>.
46. Identify and use, or adapt, screening practices for identifying individuals who may have FASD.
47. After screening and diagnosis, identify parent support groups available, both in person and online, for individuals and families affected by FASD.
48. Identify possible sources of funding for obtaining diagnoses of all types of FASD.

Legal and Judicial Reform

49. Ensure that there is relevant information for individuals, agencies, and organizations that represent the interests of children on different issues in addressing FASD (i.e., legal and court personnel).
50. Ask state Court Improvement Programs to do trainings on FASD.
51. Consider FASD in juvenile/criminal sentencing.
52. Use judicial case review hearings to review the developmental progress of each child affected by any form of FASD.
53. Disseminate a model law on the diagnosis, prevention, and treatment of FASD.
54. Develop a law school clinic focused on FASD (possibly out of a clinic that specializes in disabilities).
55. Use the term “training and education” instead of simply “training” to assist in the development of FASD-related curricula for bar associations, law schools, etc.

Engagement of Multiple Systems

56. Emphasize prevention of FASD in the child welfare and education systems.
57. Develop integrated systems of care to assist children with FASD in the places where they gather (like schools).
58. Bring up the topic of FASD with state Children's Justice Act Committees that already should be focusing on child abuse victims with disabilities.

Expanding the National Consciousness

59. Conduct a national campaign around FASD.
60. Think about how to get information about FASD to those who need it and how to tailor the information to different audiences (social media, etc.).
61. Educate the public about the risks of a mother's use of alcohol in pregnancy.
62. Conduct trainings on FASD for families, extended families, and youth.
63. Develop a plan to bring biological parents into the discussion about FASD.
64. Provide FASD training and support for biological, adoptive, and foster families.
65. Train Early Childhood Home Visitation Program workers on FASD.
66. Include tribal governments and state committees that address youth services in training/education on FASD.
67. Make all FASD training culturally appropriate.
68. Develop appropriate ways to talk to children about FASD.
69. Provide information about addiction and recovery support to professionals working with adults and children affected by FASD.
70. Have FASD better understood by the child welfare system.
71. Include medical personnel in designing programs to help young people with FASD.
72. Incorporate information about FASD into trauma trainings.
73. Develop a chart or put together information on the differences between FASD and autism spectrum disorders.
74. Conduct a cost-benefit analysis of untreated FASD to show the value of investing in treatment programs for those with FASD.
75. Assure provision of postadoption services to serve families affected by children with FASD.
76. Use the resources of the National Organization on FAS program and the Circle of Hope/Birth Mothers Network for engaging the biological mothers of those with FASD.

Appendix D: Additional Resources on Evidence-Based Interventions To Address FASD

Adnams, C.M., et al. 2007. Language and literacy outcomes from a pilot intervention study for children with fetal alcohol spectrum disorders in South Africa. *Alcohol* 41(6):403–414. doi: S0741-8329(07)00133-4 [pii] 10.1016/j.alcohol.2007.07.005.

Bertrand, J. 2009. Interventions for children with fetal alcohol spectrum disorders: Overview of findings for five innovative research projects. *Research in Developmental Disabilities* 30(5): 986–1006. doi: 10.1016/j.ridd.2009.02.003.

Coles, C.D., Kable, J.A., and Taddeo, E. 2009. Math performance and behavior problems in children affected by prenatal alcohol exposure: Intervention and follow-up. *Journal of Developmental and Behavioral Pediatrics* 30(1):7–15. doi:10.1097/DBP.0b013e3181966780. [PMID: 19194327].

Coles, C.D., Strickland, D.C., Padgett, L., and Bellmoff, L. 2007. Games that "work": Using computer games to teach alcohol-affected children about fire and street safety. *Research in Developmental Disabilities* 28(5):518–530. doi: S0891-4222(06)00069-2 [pii]10.1016/j.ridd.2006.07.001.

Collaborative Initiative Fetal Alcohol Spectrum Disorders. 2015. *Research*. Available at <http://cifasd.org/research/#Chambers>.

Kable, J.A., Coles, C.D., and Taddeo, E. 2007. Socio-cognitive habilitation using the Math Interactive Learning Experience (MILE) program for alcohol-affected children. *Alcoholism: Clinical and Experimental Research* 31(8):1425–1434. doi: 10.1111/j.1530-0277.2007.00431.x [PMID: 17550365].

Loomes, C., Rasmussen, C., Pei, J., Manji, S., and Andrew, G. 2008. The effect of rehearsal training on working memory span of children with fetal alcohol spectrum disorder. *Research in Developmental Disabilities* 29(2):113–124. doi: 10.1016/j.ridd.2007.01.001.

National Institute on Alcohol Abuse and Alcoholism. 2015. *Research: Fetal Alcohol Spectrum Disorders*. Available at www.niaaa.nih.gov/research/major-initiatives/fetal-alcohol-spectrum-disorders.

O'Connor, M.J., et al. 2006. A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology* 74(4):639–648.

Paley, B., and O'Connor, M.J. 2011. Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Research and Health* 34(1):64–75.

Warren, K.R., Hewitt, B.G., and Thomas, J.D. 2011. Fetal alcohol spectrum disorders: Research challenges and opportunities. *Alcohol Research & Health* 34(1):4–14.

