



Advocating for Individuals and Families Living with Fetal Alcohol Spectrum Disorders (FASD)

Judicial College Education and Conference Center

Annapolis, Maryland

January 27, 2017

8:00 a.m. – 8:30 a.m.	REGISTRATION & CONTINENTAL BREAKFAST
8:30 a.m. - 8:45 a.m.	<p>Welcome <i>Ed Kilcullen, Executive Director, Maryland CASA Association</i> Moderator: <i>Tom Donaldson, President, National Organization on Fetal Alcohol Syndrome</i></p>
8:45 a.m. – 9:30 a.m.	<p>A Disability By Any Other Name: Why Children with FASD Have Not Been Diagnosed and Treated (and What You Can do About It!) <i>Dr. Douglas Waite, MD, Medical Director, The Keith Haring Clinic, Children’s Village</i></p>
9:30 a.m. – 10:30 a.m.	<p>Fetal Alcohol Spectrum Disorders: What’s New and What You Should Do! <i>Dr. Larry Burd, Ph.D., Director, North Dakota Fetal Alcohol Syndrome Center</i></p>
10:30 a.m. - 10:45 a.m.	MORNING BREAK
10:45 a.m. – 11:45 a.m.	<p>Identifying Children and Youth with FASD in the Child Welfare & Juvenile Justice Systems <i>William Edwards, Esq., Deputy Public Defender III, Office of the Public Defender, Los Angeles County</i></p>
11:45 a.m. – 12:30 p.m.	<p>FASD: Healing Families and Communities <i>Kathy Mitchell, MHS, LCADC, Vice President, National Organization on Fetal Alcohol Syndrome (NOFAS)</i></p>
12:30 p.m. – 1:30 p.m.	LUNCH
1:30 p.m. – 2:15 p.m.	<p>Special Education Issues for Students with FASD <i>Leslie Seid Margolis, J.D., Managing Attorney, Disability Rights Maryland, & Diane Smith Howard, J.D., Senior Staff Attorney, National Disability Rights Network</i></p>
2:15 p.m. – 3:00 p.m.	<p>Representing Juveniles with FASD: A Multi-Disciplinary Approach <i>Lori James-Townes, LCSW-C, Director of Social Work, Leadership and Program Development, MD Office of the Public Defender, & Meredith Jossi, LCSW-C, Social Work Supervisor, MD Office of the Public Defender</i></p>
3:00 p.m. – 3:15 p.m.	AFTERNOON BREAK
3:15 p.m. – 4:15 p.m.	<p>FASD in Maryland: What’s Available, What Do We Need & Where Do We Go From Here? <i>Panel: Kathy Mitchell, MHS, LCADC, Leslie Seid Margolis, J.D., Diane Smith Howard, J.D., Lori James-Townes, LCSW-C, Dr. Larry Burd, Ph.D., William Edwards, Esq., Dr. Douglas Waite, M.D.</i></p>
4:15 p.m. – 4:30 p.m.	<p>CLOSING <i>Ed Kilcullen, Executive Director, Maryland CASA Association</i></p>

Agenda subject to change

Session Descriptions

Time: 8:45 a.m. – 9:30 a.m.

Title: A Disability by Any Other Name: Why Children with FASD Have Not Been Diagnosed and Treated (and What You Can Do About It!)

Presenter: *Dr. Douglas Waite, MD, Medical Director, The Keith Haring Clinic, Children’s Village*

Description: Over four decades since its first description in 1973, fetal alcohol spectrum disorders are now known to be the most common cause of intellectual disability with prevalence of at least 1% in the general population and an even greater prevalence among children in foster care and the juvenile justice system. This session will focus on the history of FASD to describe not only how FASD is diagnosed, but also why to date, so few children are being diagnosed. Subsequent discussion will address the need for FASD specific interventions in the community and directions for advocacy.

Goals:

1. Participants will gain an understanding of the criteria for diagnosing fetal alcohol spectrum disorders and the specific neurobehavioral challenges of children and adults with this disorder.
2. Participants will gain perspective of the difficulties and barriers to diagnosis, including the role of stigma against persons with substance use disorder in our society.
3. Participants will gain an understanding of FASD-specific interventions and the need for advocacy for diagnosis and services.

Time: 9:30 a.m. – 10:30 a.m.

Title: Fetal Alcohol Spectrum Disorders: What’s New and What You Should Do!

Presenter: *Dr. Larry Burd, Ph.D., Director, North Dakota Fetal Alcohol Syndrome Center*

Description: This presentation will review current rates of prenatal alcohol exposure and screening for exposure during pregnancy. The talk will include recent developments in screening for FASD, diagnosis of FASD and strategies for management of people with FASD.

Goals:

1. Participants will become familiar with current concepts about prevalence of FASD
2. Participants will gain an understanding of current concepts of prevalence, screening and management of people with FASD.

Time: 10:45 a.m. – 11:45 a.m.

Title: Identifying Children and Youth with FASD in the Child Welfare & Juvenile Justice Systems

Presenter: *William Edwards, Deputy Public Defender III, Office of the Public Defender, Los Angeles County*

Description: Many families enter the child welfare system through the dependency and delinquency courts due to drug and alcohol abuse. FASD/ND-PAE should be a primary “rule out” in these cases. Neurocognitive and neurobehavioral issues will impact a child’s actions in foster care, educational settings, juvenile court, and community agency settings. A child with FASD/ND-PAE growing up without a proper diagnosis deprives the child of adequate services or effective treatment to prevent recidivism and further involvement with the juvenile court system. This presentation will discuss the neurobehavioral, neurocognitive, medical, mental health and neurological problems these children face across the life span.

Goals:

1. Participants will be able to identify red flags to help get children screened and diagnosed.
2. Participants will learn about the challenges of working with children with FASD and better understand this misunderstood, misdiagnosed and underserved population.

Session Descriptions

Time: 11:45 a.m. – 12:30 p.m.

Title: FASD: Healing Families and Communities

Presenter: *Kathy Mitchell, MHS, LCADC, Vice President, National Organization on Fetal Alcohol Syndrome (NOFAS)*

Description: All family members are impacted in different ways when discovering that FASD has affected a loved one. Family members may experience denial, guilt, shame, grief and hopelessness. Fear and guilt can translate to blame and anger towards the birth mom, other family members, and even the adult (or child) with FASD for having disabilities. Birth families may experience tremendous guilt and shame that can become permanent and pervasive. Assisting families through the process of acceptance that includes education, counseling and strength-based parenting strategies will increase the likelihood of long-term recovery for the family system.

- Goals:**
1. Participants will learn about bias, stigma, values and ethics around women who use substances while pregnant.
 2. Participants will gain an understanding of the family dynamics of families living with addictions.
 3. Participants will learn about NOFAS resources and programs for families impacted by FASD.
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Time: 1:30 p.m. – 2:15 p.m.

Title: Special Education Issues for Students with FASD

Presenters: *Leslie Seid Margolis, J.D., Managing Attorney, Disability Rights Maryland, & Diane Smith Howard, J.D., Senior Staff Attorney, National Disability Rights Network*

Description: Session will address “red flag” special education issues for students with FASD in the school to prison pipeline and for those in the foster care system, and will discuss the role of, and possible assistance available from, the protection and advocacy system.

- Goals:**
1. Participants will gain an understanding of critical special education issues affecting students involved in the court system;
 2. Participants will gain an awareness of resources available to assist those working with students with FASD who are involved in the court system.
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Time: 2:15 p.m. – 3:00 p.m.

Title: Representing Juveniles with FASD: A Multidisciplinary Approach

Presenter: *Lori James-Townes, LCSW-C, Director of Social Work, Leadership & Program Development, MD Office of the Public Defender, & Meredith Jossi, Social Work Supervisor, MD Office of the Public Defender*

Description: Representing juveniles with FASD presents unique challenges for the defense team. This session will describe the role of the social worker and other integral members of the team when working with youth with FASD and their families in and out of the court.

- Goals:**
1. Attendees will gain an understanding of the importance of client-centered advocacy.
 2. Attendees will gain an understanding of the role of the social worker and other non-attorney members of the team.
 3. Attendees will learn strategies to advocate for services and appropriate treatment for youth with FASD.
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Session Descriptions

Time: 3:15 p.m. – 4:15 p.m.

Title: FASD in Maryland: Where Are We Now and Where Do We Go From Here?

Moderator: Tom Donaldson, President, NOFAS

Panelists: *Kathy Mitchell, MHS, LCADC, Vice President, NOFAS; Leslie Seid Margolis, J.D., Managing Attorney, Disability Rights Maryland; Lori James-Townes, LCSW-C, Director of Social Work, Leadership & Program Development, MD Office of the Public Defender; Dr. Larry Burd, Ph.D., Director, North Dakota Fetal Alcohol Syndrome Center; Dr. Douglas Waite, M.D., Medical Director, The Keith Haring Clinic, Children's Village, William Edwards, Deputy Public Defender III, Office of the Public Defender, Los Angeles County*

Description: This panel discussion will feature an overview of local and national resources available, a review of what has been done, and necessary next steps to raise awareness, promote prevention and address the needs of families impacted by FASD in Maryland. Panelists will also discuss lessons learned and progress made in other states.

Goals:

1. Participants will learn about the history of the FASD task force and progress made in preventing and addressing FASD.
2. Participants will gain an understanding of the challenges faced in bringing about appropriate diagnosis and treatment of FASD.
3. Participants will learn about efforts in other states and what can be done in Maryland to better identify, diagnose and serve children and youth with FASD and their families.
