



**MARYLAND**

**FETAL ALCOHOL SPECTRUM DISORDERS**

**STATE PLAN**

**2010-2012**

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# Maryland State Two Year State Plan 2010-2012

## Table of Contents

• Overview	3
• Background	4
• Vision, Mission and Plan Process	5
• State Goals	5
• <b>Objective I:</b> Reduce the number of babies born with FASD	6
• <b>Objective II:</b> Expand/enhance the availability and use of treatment services for children/youth with FASD	6
• Two Year Implementation Plan	7

## **Overview**

### **Introduction**

Fetal Alcohol Syndrome (FAS) was first recognized in 1973 as a collection of birth defects that included distinct dysmorphic facial features, mental retardation and other developmental disorders. Initially FAS was thought to occur only among births to alcoholic or alcohol-abusing women, but subsequent research findings showed that less obvious but equally disabling developmental disorders also resulted from prenatal alcohol exposure, known collectively as Alcohol-Related Neurodevelopmental Disorders (ARND). Another more inclusive term -- “Fetal Alcohol Effects” (FAE) -- came into wide use. Today, both FAS and FAE have been subsumed under the broader and more accurate term, Fetal Alcohol Spectrum Disorders (FASD).

Thirty years after recognition of FAS, medical and scientific consensus is that:

- Prenatal alcohol exposure is the leading known cause of mental retardation.
- Alcohol exposure at any point during fetal development may cause permanent, lifelong disabilities.
- No amount of alcohol is known to be safe during pregnancy.
- Unlike other neurodevelopment birth defects or developmental spectrum disorders, e.g. Autism Spectrum Disorders, the cause of FASD is known and 100% preventable.

In February 2005, the U.S. Surgeon General issued the first advisory on alcohol use in pregnancy since 1981. The advisory states:

- A pregnant woman should not drink alcohol during pregnancy.
- A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.
- A woman who is considering becoming pregnant should abstain from alcohol.
- Recognizing that nearly one-half of all births in the United States are unplanned, women of childbearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure.
- Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy and advise them not to drink alcoholic beverages during pregnancy.

## **FASD In Maryland**

The Centers for Disease Control and Prevention (CDC) estimates the incidence of FAS, the most extreme of the spectrum of disorders, to be in the range of from three to 22 cases per 1000 live births. The incidence and prevalence for the full spectrum of disorders is unknown. However, researchers at the University of North Dakota have developed a model for extrapolating data to generate estimated rates for rates FAS and ARND. When this methodology is applied to Maryland birth statistics, an estimated 10 cases of FASD occur per 1000 live births each year, or approximately 750 new FASD cases in Maryland per year.

The Maryland Department of Health and Mental Hygiene's Pregnancy Risk Assessment Monitoring System (PRAMS), a CDC-funded surveillance program, issued reports from surveys of new mothers annually from 2001 to 2008. The reports indicate the extent of the problem of alcohol use during pregnancy in Maryland. In 2008, 9% of Maryland PRAMS mothers reported alcohol use during pregnancy and 1.0% reported binge drinking, a slight increase over 2001 rates (8% any alcohol use and 0.6% binge drinking).

## **Background** **Maryland FASD Work Group**

In September 2003, the National Organization for Fetal Alcohol Syndrome (NOFAS) held a "Hope for Women in Recovery Summit" in Baltimore. Many key policy makers, including several Maryland legislators, attended the Summit. Delegate Pauline Menes (D-Prince George's and Anne Arundel) became a champion for FASD.

During the following session, Delegate Menes introduced a bill establishing an FASD task force. Although the bill did not move forward, DHMH and the Governor's Office on Crime Control and Prevention (GOCCAP) jointly convened the FASD Work Group in July 2004. Members were appointed representing State agencies that included the Governor's Office for Children, Youth and Families, the Department of Human Resources, the Maryland State Department of Education, the Department of Public Safety and Correctional Services, the Department of Juvenile Services, the Maryland Department of Disabilities, as well as GOCCAP and DHMH, and Delegate Menes. Private sector members included Kathleen Mitchell, Vice President and national spokesperson for NOFAS; Dr. Paula Lockhart, a child psychiatrist with the Kennedy Krieger Institute (KKI); and Janet and Dave Duncan, parents of an adult child with fetal alcohol syndrome. DHMH assumed sole responsibility for leadership and staffing of the work group in December 2004.

The FASD Work Group met monthly or more frequently from July 2004 through June 2005. Over this twelve month period, the work group invited parents and other guests to share expertise and experience in FASD; reviewed medical literature and reports; considered how other states were addressing FASD; developed a Vision, Mission, and Goals for a broader statewide FASD Coalition; and made recommendations concerning suggested action plans for FY 2006 and 2007.

# THE MARYLAND FASD COALITION

## Vision

We envision a Maryland where Fetal Alcohol Spectrum Disorders (FASD) are rare and identified as early as possible to minimize disability and maximize the quality of life for affected individuals and their families.

## Mission

The Coalition mission is to prevent FASD and create an enduring, integrated system of care for individuals and their families that assure lifelong access to services that are comprehensive, coordinated, continuous and culturally appropriate.

## Plan Process

During the past years The Maryland FASD Coalition identified immediate needs, gaps and barriers relating to FASD prevention and intervention in the State of Maryland. The primary barriers regarding the prevention of FASD are:

- Lack of awareness by physicians, mental health professionals, school officials, and social services workers of FASD
- Lack of knowledge of FASD by expectant mothers
- Low reliability of mother self-report
- Lack of uniform identification of babies born to at-risk mothers
- Limited data and statistics on FASD prevalence

The identified primary barriers regarding FASD intervention are:

- Limited FASD screening and assessment capabilities in the state
- Limited FASD diagnostic capability in the state
- Lack of integration of FASD into individual treatment plans
- Limited data/statistical collection for diagnosis and treatment outcomes
- FASD not being identified as a diagnosis

## Goals

The Coalition developed more than 10 goals that we want to accomplish. However, during several detailed meetings, the Coalition decided on four goals with a specific rationale:

**Goal 1.** All Marylanders will understand the dangers of any alcohol use during pregnancy.

**Rationale:** Decrease the number of women who drink alcohol before and during pregnancy

**Goal 2.** All Marylanders will understand the impact of FASD on the Maryland workforce and economy.

**Rationale:** Increase awareness of FASD and gain public support.

**Goal 3.** All Marylanders will have access to diagnosis, treatment and support services for FASD.

**Rationale:** Increase identification and diagnosis of individuals who have FASD.

**Goal 4.** Marylanders who need access to screening, treatment or support services for FASD will not be hampered by stigma or discrimination.

**Rationale:** Determine and monitor the incidence and prevalence of FASD in Maryland. Expand and improve services to FASD individuals.

## TWO YEAR PLAN

Strategies	Activities
<b>Objective I: Reduce the number of babies born with FASD</b>	
1. Increase public awareness of FASD and risks of drinking during pregnancy	<ul style="list-style-type: none"> <li>• FASD Website</li> <li>• Update PRAMS data</li> <li>• Community Health Fairs/Presentations</li> <li>• Consumer/Professional Brochures</li> <li>• Educating Substance Abuse Counselors</li> <li>• Grants</li> <li>• Provider Education (private/non-private physicians)</li> <li>• Media Campaign (billboards, public TV ads)</li> <li>• Educational Giveaways: pens, coasters, etc.</li> </ul> <p><b>Partnerships:</b></p> <ul style="list-style-type: none"> <li>• Girl Scouts of America-</li> <li>• Youth Groups and Organizations</li> <li>• TEXT4BABY</li> <li>• Grand Rounds</li> <li>• Develop a girl scout's badge</li> <li>• Managed Care organizations</li> <li>• College and sorority organizations</li> <li>• Local Health Departments</li> </ul>
2. FASD recognized as a diagnosis	<ul style="list-style-type: none"> <li>• Educate school health nurses, therapists, and clinicians on FASD</li> <li>• Diagnostic assessments and on-going case management services</li> <li>• Work with Medicaid and managed care organizations to ensure coverage of related FASD Services</li> </ul>
<b>Objective II: Expand/enhance the availability and use of treatment services</b>	
1. Establish broad-based identification, screening, and diagnosis of children/youth with FASD	<ul style="list-style-type: none"> <li>• Provide ongoing training on FASD identification, screening, and referral</li> <li>• Promote identification of at-risk moms by medical professionals</li> </ul>
2. Integrate FASD intervention services into appropriate treatment and service plans	<ul style="list-style-type: none"> <li>• Educate providers on appropriate interventions for inclusions on treatment plans</li> <li>• Identify organizations and processes in which integration is appropriate</li> </ul>
3. Identify/address FASD intervention service and support availability throughout the state	<ul style="list-style-type: none"> <li>• Develop resource guide identifying services</li> <li>• Integrate advocacy and other support for and by families</li> </ul>

## TWO YEAR IMPLEMENTATION PLAN

Strategy	Activities	Who	Measurable Outcome
1. Increase public awareness of FASD and risks of drinking during pregnancy	<ul style="list-style-type: none"> <li>• FASD Website</li> <li>• Community Health Fairs</li> <li>• Professional Brochures</li> <li>• Educational Giveaways: pens, coasters, etc.</li> <li>• <b>Partnerships:</b></li> <li>• Girl Scouts of America-Develop a girl scouts badge</li> <li>• Managed Care Organizations</li> <li>• Local Health Departments</li> </ul>	Maryland FASD Coalition Community	Decrease the number of women drinking during pregnancy
2. FASD recognized as a diagnosis	<ul style="list-style-type: none"> <li>• Educate school health nurses, therapists, and clinicians on FASD Diagnostic assessments and On-going case management services</li> </ul>	Maryland FASD Coalition Physicians/Nurses Health care providers	Increase the number of FASD individuals receiving care
	<ul style="list-style-type: none"> <li>• Work with Medicaid and managed care organizations to ensure coverage of related AFSD Services</li> </ul>	DHMH- Medicaid	Increase the number of FASD individuals receiving care
3. Establish broad-based identification, screening, and diagnosis of children/youth with FASD	<ul style="list-style-type: none"> <li>• Provide ongoing training on identification, screening, and referral</li> </ul>	Maryland FASD Coalition HealthCare Providers	Increase the number of FASD individuals receiving care
	<ul style="list-style-type: none"> <li>• Promote identification of at-risk moms by medical professionals</li> </ul>	Maryland FASD Coalition Community	Increase the number of FASD individuals receiving care
4. Integrate FASD intervention services into appropriate treatment and service plans	<ul style="list-style-type: none"> <li>• Educate providers on appropriate interventions for inclusions on treatment plans</li> </ul>	Maryland FASD Coalition Physicians/Nurses Health care providers	Increase access to care
	<ul style="list-style-type: none"> <li>• Identify organizations and processes in which integration is appropriate</li> </ul>	Maryland FASD Coalition	Increase access to care
5. Identify/address FASD intervention service and support availability throughout the state	<ul style="list-style-type: none"> <li>• Develop resource guide identifying services</li> <li>• Integrate advocacy and other support for and by families</li> </ul>	Maryland FASD Coalition	Reduce health disparities in the access of care