

REPORT ON EFFORTS TO PREVENT AND COMBAT FETAL ALCOHOL SYNDROME AS WELL AS DEFICIENCIES IN EFFORTS TO REDUCE THE INCIDENCE OF FETAL ALCOHOL SYNDROME

(FY2014 Appropriation Bill - Public Act 59 of 2013)

April 1, 2014

Section 502: The department shall explore developing an outreach program on fetal alcohol syndrome services. The department shall report to the senate and house subcommittees on community health by April 1 of the current fiscal year on efforts to prevent and combat fetal alcohol syndrome as well as deficiencies in efforts to reduce the incidence of fetal alcohol syndrome.

*Michigan Department
of Community Health*



**Rick Snyder, Governor
James K. Haveman, Director**

FETAL ALCOHOL SYNDROME
Department of Community Health Boilerplate Report
Section 502

Purpose:

This report, prepared through a joint effort of the Behavioral Health and Developmental Disabilities Administration and the Public Health Administration, addresses Section 502 of the FY 14 Department of Community Health Appropriations Bill, Public Act 59 of 2013.

Background:

- The institute of Medicine Report to the U.S. Congress (1996) stated: “Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”
- Fetal Alcohol Syndrome (FAS) is a brain-based birth defect reportable to the Michigan Birth Defects Registry. A diagnosis of FAS has three major components: distinctive facial features, growth deficiencies, and brain damage. Only FAS has diagnostic guidelines.
- Prevalence of FAS in the U.S. is estimated to be between 0.5—2 per 1000 births.
- The cost to the nation of FAS alone may be up to \$6 billion each year. For one individual with FAS, the lifetime cost is at least \$2 million.
- Michigan Department of Community Health Substance Abuse Treatment Policy #11 states: “Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.”
- Scientists believe that there are at least three times as many cases of FASD as FAS.
- The effects that result from FASD range from mild to severe at birth; it is a brain/neurological disorder that cannot be cured or reversed, and can have co-occurring psychiatric disorders. Additionally, alcohol related congenital anomalies of the heart, renal and skeletal systems can occur as well as eye and hearing malformations.
- “Children with FASD are often thought to be defiant, aggressive, or out of control; in fact, they likely have central nervous damage typical of FASD. Cognitive deficits and impaired executive function may make them poor learners.”¹
- FASD are the group of disorders most frequently cited as the most common preventable birth defect, and more can be done to help increase public awareness of FASD and the importance of prevention of prenatal alcohol exposure/ alcohol use during pregnancy, early identification and education of at-risk women 15-44 years of age, and access to alcohol treatment.²
- The provision of promising or evidenced based education, alcohol screening , supports, intervention and treatment strategies to assist at risk women and their partners is critical to

¹ “Improving Awareness and Treatment of Children with Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders”, The Disability Service Center JBS International, Inc., June 2013.

² “Improving Awareness and Treatment of Children with Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders”, The Disability Service Center JBS International, Inc., June 2013.

improvement in functioning as well as support to families and future generations to prevent FASD.

- For babies and infants exposed to prenatal alcohol, early childhood periodic, screening, identification, referral and diagnosis of an FASD is one of the main protective factors in decreasing adverse life outcomes (e.g., trouble with the law, confinement in jail, or for treatment, inappropriate sexual behavior, substance abuse).³
- The provision of promising or evidenced based intervention/supports/strategies to assist the child with FASD following early diagnosis is critical to improvement in functioning as well as is support to families to manage the disability.
- There are increasing life challenges for individuals with FASD as they grow older. Regardless of the level of severity at birth, the condition becomes increasingly problematic for each child/adult as age increases and support/interventions are required throughout the life course from multiple systems--health care, education/special education, behavioral health, juvenile justice, child welfare, housing, corrections.
- Investment in prevention, early diagnosis and intervention/supports for women, infants and families is cost effective in comparison to the costs of adverse outcomes of substance abuse addiction and morbidity as well as special education, juvenile justice or jail confinement, residential treatment or psychiatric hospitalization.
- FASD contributes greatly to infant morbidity and the actions in the Infant Mortality Reduction Plan addresses overall promotion of healthy pregnancy outcomes and healthy, growing, thriving infants that include educational messages to pregnant women and women of child bearing age as well as to fathers to avoid alcohol consumption to prevent FASD.

The following outline provides a preliminary description of some of the resources, activities and programs targeted to FASD within MDCH that are currently in place for promotion, prevention and intervention/supports for pregnant women, children/youth and adults; and an initial identification of future enhancement options for consideration. The use of the terms promotion, prevention and intervention/supports are defined below.

Promotion

Promotion means educating the general public or a whole population group that has not been identified on the basis of individual risk.

Current Resources/Activities:

- Medicaid Policy requires the use of a validated substance abuse risk assessment at each preventive pediatric health care visit beginning at 11 years of age and appropriate follow up action if the risk assessment is positive.
- The Maternal Infant Health Program (MIHP) Medicaid home visiting program utilizes an evidence-based alcohol specific screening and motivational interview tool to screen,

³ Streissguth, A. P., Bookstein, F.L., Barr, H.M, et al. Risk factors for adverse life outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Developmental and Behavioral Pediatrics* 25:228–238, 2004.

identify and refer to treatment at risk women to improve and promote healthy pregnancy outcomes.

Future Enhancement Considerations:

- Increased utilization of validated substance abuse risk assessment tools during health care and mental health care visits for youth and women of childbearing age.
- Comprehensive marketing/media campaign strategy including health promotion/public service announcements to the general public to provide education about the risks of drinking while pregnant. The Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence website provides materials that can be used in a comprehensive marketing/media campaign in Michigan.

Prevention

Prevention means activities/programs that are effective in addressing attitudes and behavior among individuals or subgroups at risk due to certain social, environmental or biological factors. For example, trauma is a predisposing factor for women who drink during pregnancy and as an after effect for children diagnosed with FASD. In one study in Washington State, 96% of the women who had given birth to at least one child with fetal alcohol syndrome (FAS), had at least one mental disorder and 95% had a history of sexual or physical abuse.⁴

Current Resources/Activities:

- Women Specialty Services (WSS), substance use disorder treatment programs, screen children for FASD and refer them for diagnosis as well as provide education and programming regarding FASD prevention as a policy and contract requirement for all substance abuse treatment programs that serve women.
- Two counties, Kent and Muskegon, offer extended case management services to women with substance use disorders who are at risk of having an FASD birth, or who have a child less than one year with FASD.
- An intradepartmental workgroup is developing an on-line training course for health care providers to be well versed and trained on how to educate/screen/counsel to prevent alcohol consumption during pregnancy; how to best educate and encourage pregnant women and those of child bearing age to abstain from alcohol consumption during pregnancy and how to intervene with evidence based treatment options if alcohol use is present during pregnancy.
- A community-based grantee workgroup comprised of Department of Community Health intra departmental staff, birthing hospital managers, an obstetrics and gynecology physician network and an FASD certified trainer has provided culturally appropriate education/screening/intervention to at risk Medicaid clients with bi-lingual needs and co-occurring mental health disorders.

⁴ "Improving Awareness and Treatment of Children with Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders", The Disability Service Center JBS International, Inc., June 2013.

- Eight community-based organizations deliver locally identified services, provide culturally sensitive prevention education to pregnant women and at risk women of childbearing age, hire certified FASD trainers and provide family support services.
- A Native American community-based health clinic provides alcohol screening/brief motivational interviewing/referral for at risk women and screens their infant children for prenatal alcohol exposure/referral to an FASD diagnostic center.
- The community-based grants link at risk women to substance abuse counseling and treatment and affected infants and children identified with prenatal alcohol exposure to existing early childhood programs: Early On, Early Head Start, Head Start, Parents as Teachers, Infant Mental Health, Tribal Home Visiting. These programs assure identified children receive coordination and support to access community-based resources and/or the FASD diagnostic centers for further assessment and evaluation.

Future Enhancement Considerations:

- Increased FASD screening and referral activity at Women's Specialty Services (WSS) co-ed programs.
- Education to physicians, teachers, mental health clinicians, Department of Human Services (DHS) workers, other relevant professionals, general public educators to provide focused, proactive education and outreach to high risk women who are most adversely impacted by life stressors, trauma and social determinants of health regarding the risks of using alcohol at the time of conception and during pregnancy.
- Behavioral health providers include substance abuse risk assessment and FASD screening as part of their initial intake for services.
- Substance abuse screening/early identification/referral and treatment for infants and children in child protective services and foster care.
- All home visiting programs across departments and public programs need to implement use of evidence-based and relevant screening/early identification/referral and treatment support for women, infants and families affected by prenatal alcohol exposure.

Intervention and Support Across the Life Span

Intervention means providing treatment and support to individuals who are identified as having a diagnosed condition.

Current Resources/Activities:

- Diagnosis before age 6 improves the chances of an individual achieving developmental potential. Presently MDCH provides mini grants to support a part-time coordinator at major medical facilities that have on staff the medical specialty practitioners needed to operate a FASD diagnostic center. (Centers are located in the cities of Marquette, Grand Rapids, Kalamazoo, Ann Arbor and Detroit.)
- MDCH has provided educational (supplemental) grants to all five FASD Diagnostic Centers of Excellence over the past three years that have been utilized to implement university medical school curriculum for pediatricians related to FASD.

- Services provided through the Community Mental Health Services Programs (CMHSPs)/Pre-paid Inpatient Health Plans (PIHPs) target at-risk mothers and their infants/toddlers through the provision of home-based infant mental health services. Other services provided for youth and families include: Trauma Focused Cognitive Behavioral Therapy to remediate the impact of trauma in children and prevent the likelihood of alcohol abuse as an adult; Parent Management Oregon Model which provides parents with the skills to address the challenging behaviors of their child/youth. Parent Support Partners also address skill development of the parent who needs to advocate for services for their child and provide the support needed to lessen the parent's stressors and thereby mitigate the likelihood of abuse or neglect.
- MDCH currently provides training to CMHSP staff in Trauma Recovery Empowerment Model (TREM). TREM is a group model for women with mental health disorders and trauma history.
- Persons with FASD may receive public behavioral health services throughout adulthood if they meet eligibility as having an intellectual and developmental disability. Intellectual and developmental disability means the person has substantial functional limitations in at least three of seven areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

Future Enhancement Considerations:

- Sufficient capacity of the five FASD diagnostic clinics to meet the demand for diagnostic evaluations. Additionally, the diagnostic process is costly and resources are needed to help families manage the cost of diagnosis. The current diagnostic clinics focus almost exclusively on diagnosis with no assistance to families regarding interventions or behavioral management and coordination of services with the school system.
- On-going education and training of community mental health clinicians and providers, pediatricians, obstetricians and medical home providers, including psychiatric facilities (i.e. Hawthorn Center), regarding FASD, promising practices and evidenced based treatment(s) that are found to be effective with children with FASD.
- Without the guidance of a case manager and other services from the behavioral health system, someone entering adulthood with FASD does not usually have enough support to become a productive member of society. Michigan does not currently provide services and supports specifically addressing the unique challenges of FASD for an adult who may find it difficult to obtain work, hold down a job, and find housing. Due to poor executive functioning and judgment related to their neurological disorder, someone with FASD can often become entangled with the justice and correctional systems.
- Treatment interventions for adults in the behavioral health system, especially substance abuse treatment, are lacking. This can lead to a generational type of FASD where women with FASD have an addiction to alcohol and give birth to infants

- with FASD. They struggle with traditional substance abuse treatment because of their own FASD and rarely achieve recovery without additional interventions.
- Comprehensive education and training for providers of services to children (Early On, schools, teachers, juvenile justice system, child welfare) regarding FASD in order that children be appropriately identified, diagnosed and provided treatment and support services rather than misdiagnosed and thereby defaulting to more restrictive, costly placements including institutions.

Summary and Recommendations:

In conclusion, it is critical to understand that FASD is a 100% preventable lifelong disability that comes with huge costs for the individual and their families, society and health, behavioral health, education, child welfare, juvenile justice and corrections systems. Opportunities have been identified in this report to promote understanding of and prevent this condition through reaching the public, key professional groups and particularly women of reproductive age. It is of significance importance that screening be accessible to all those at risk, with resulting engagement in needed support/intervention services prior to and during pregnancy. First and foremost by a concerted, comprehensive effort aimed at promotion and prevention activities to prevent alcohol use during pregnancy. As outlined in this report, the Department is engaged in a number of activities aimed at FASD prevention, targeting at risk populations, providing support for diagnosis and treatment, but opportunity exists to enhance efforts and strategies built upon increasing bodies of research and evidence.

The altered life course of children and adults with FASD should continue to be addressed at an appropriate level of need and earlier in each individual's life, preferably in infancy. Considerable resources are being expended across systems over a lifetime for these individuals in restrictive settings and ineffective placements. Much additional focus on early identification is needed so that supports and evidenced based and informed interventions are begun as early as possible to help address the cognitive, behavioral, co-occurring psychiatric disorders and social challenges that become more costly in both human and monetary terms the longer they remain unaddressed or inadequately addressed.

The Department of Community Health Administrations on Behavioral Health and Developmental Disabilities and Public Health are partnering to develop a more complete assessment of the incidence and costs related to FASD in Michigan across systems, including a more systematic identification of what supports and evidence based or evidence informed practices and/or programs are needed.

1. Based upon that analysis, MDCH will develop a set of recommendations to implement a strategic work plan to:
 - a. Improve promotion and prevention activities for FASD, for example as was done in the Safe Sleep campaign. Once increased resources and activities were in place to inform parents and caregivers about these preventable deaths, the numbers began to significantly decrease.

- b. Identify and implement a more effective and efficient life-long continuum of supports and services for individuals impacted by FASD and their families.
2. This report including analysis, recommendations and key strategies for a work plan will be completed by August 1, 2014 in order to inform budget development for FY 16.